“Autistic women have always been here”:

Autistic Women Story Their Schooling Experiences

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ABSTRACT

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Autism has been constructed as a White male category. Currently, the prevalence ratio is 4 males to every 1 female diagnosed with autism. Historically, research studies supported these gender diagnostic gaps by claiming a genetic or hormonal causation. However, more recent research suggests that the gap in diagnosis is the cause of diagnostic bias, and instead, autism looks very different in women and girls compared to boys. Because autism is assumed to be a male category, autism intervention supports in schools do not reflect the needs of autistic girls.

Missing from autism research are the narratives, perspectives, and expertise of autistic people and their care networks. The majority of autism research today comes from the psychological and epidemiology fields and examines causation and the biological factors of autism. Autism is constructed as a problem to be "solved" and the autistic person as someone to be "cured." The majority of autism research is *about* autistic people rather than *with* autistic people. This research is framed by an intersectional Disability Studies (DS) theoretical stance that forefronts the experiences of disabled people and understands disability to be an essential aspect of a person's identity, rather than a problem to be solved. Working narratively through multimodal data collection, this study privileges the sense making of three autistic women and

honors their forms of expression and communication. The study also includes the perspectives of the participants' mothers as essential aspects of their care networks. Through their stories, the expertise of autistic women is honored as essential to all conversations regarding schooling interventions for autistic youth. By exclusively focusing on women, I challenge the myth of autism as a male category and challenge a positivist autism research approach that ignores gender altogether.

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Chapter I: INTRODUCTION TO THE STUDY

Vignette #1: The Micro

"You've got to really feel the music," Joelle instructed me as she lovingly clutched her hands to her heart. "Remember you are Grizabella! You are an old cat that was once beautiful but now you're all washed up. You've been cast out. Nobody likes you! You're so sad and thinking about your life!"

A small white iPod doc blasted "Memory" from the musical *Cats* (Weber, 1981). It was Wednesday afternoon, time for our CATs musical group meeting. The group consisted of Joelle, a 15-year-old young autistic woman,[1] and myself. Joelle loved the musical *Cats*. She was an expert on the subject and was providing me with essential character backstory to inform my performance. My voice crackled and she smiled and gave me an assured thumbs-up as I attempted to hit every painful high note during the crescendo of the song. The walls of my postage stamp-sized office, located in a private school for autistic students, was plastered with yellow sticky paper with lists of character traits and descriptions. "Rum Tum Tugger is the hot guy like Justin Bieber and Paul McCartney," one says under a picture of an actor in full tiger face paint and cat suit.

In college, I began working with autistic students, and after I graduated, I began working as an early interventionist for children under the age of 3 who were flagged for displaying neurodevelopmental differences. During my first year in the field, I had approximately 12 students. All of the students were later diagnosed with autism. Of the 12 toddlers, 11 were boys.

[1] Historically, psychologists and special educators have advocated for using "person-first" language and have preferred the term "person with autism." However, throughout this research, I have chosen for several reasons to refer to my participants and the community as *autistic* or *autistic woman/man/non-binary person* rather than as a person with autism. These reasons are discussed in depth in the last section of this chapter, "Use of Terms."

When I became a classroom teacher in a school designed for students with autism, I taught several classes of all male students. Of approximately 150 students, only 10 were girls. This meant that most often they were the only girl, or one of two girls, in a classroom. As my role changed from a teacher to a supervisor, I was struck by the ways in which an emergent constructivist curriculum excluded the girls, mostly because there were so few of them in classrooms. The school philosophy centered student interests; however, in classrooms that were 90% male, those interests were frequently stereotypically male and included trains, dinosaurs, or subway/transportation studies. Class discussion involved deep analysis of video gaming systems and debates over subway commuting practices. Although some of the girls shared these interests, many did not. They were often left out of these discussions and would frequently look down or physically remove themselves by sitting on the edge of the group.

I felt drawn to these girls who were made invisible, even in a space that was supposedly designed to respond to their interests and needs. I decided to create small affinity "girls' groups" around shared interests in order to provide more space for autistic girls. The first year, the group consisted of Joelle and me as we planned out our *Cats* musical. (This speaks to the small number of girls in the school.) Eventually, this "girls' group" attracted the attention of another student, a boy, and he ended up joining our group a few weeks before the end-of-the-year performance. During the following year, the girls' group increased to two girls. We started doing karaoke versions of Justin Bieber and Lady Gaga pop hits in my cramped office. These pockets of time created opportunities for these girls to be centered in a school space that did not center them. These girls' interests and their positionalities were often swallowed up in their home classrooms where they were either one of two girls, or the only girl.

Vignette #2: The Macro

Each year, the United Nations headquarters, based in New York City, holds a World Autism Awareness Day to raise key issues in the autism community worldwide. The most recent summit, April 5th, 2018, was dedicated specifically to "empowering women and girls with autism and involving them and their representative organizations in policy and decision making to address these challenges" (UN World Autism Awareness Day, April 2nd, 2018). The UN outlined key issues of access and equity for autistic women, including educational disparities; low employment rates; and high rates of sexual, psychological, and emotional violence (UN World Autism Awareness Day, April 2nd, 2018).

I was fortunate to attend the summit and was struck by the visibility of autistic women. Throughout the day-long event, at least half of the panelists were autistic women who were self-advocates, researchers, or activists. Over and over, there were calls from autistic advocates and researchers as well as allistic[2] researchers and policymakers to increase visibility for autistic women and girls. Autistic women's stories, perspectives, and expertise, they argued, were going unexplored, unacknowledged, or ignored as White male autistic voices dominated conversations around autism. Julia Bascom, Executive Director of the Autism Self-Advocacy Network, was one of the most powerful voices that day and is the source of the quote for the title of this project. She poignantly demanded that others catch up to what autistic women have known for a long time:

> The reality is autistic women have always been here. We've always been everywhere. We're being noticed more now, which is new, but our existence and our strength and our vibrancy and the complexities and trials and joys of our life have always gone on regardless of who sees us.[…] We still talk about autism as an "extreme male brain," as though autistic women and girls don't exist, as though autistic people aren't more likely to inhabit the whole range and complexity of the gender spectrum, as though trans

[2] Allistic refers to non-autistics and is explained in more detail at the end of the chapter.

> autistic women and girls aren't a crucial part of our community. We still see significant underdiagnosis in communities of color, and we still have yet to truthfully confront the role racism plays in that. A diagnosis is still far too often dependent on access to certain resources and income, and the end result is that all across the globe, autistic women and girls are missed, overlooked, and ignored. (Addressing the UN on April 2nd, 2018)

What is to be done to address these kinds of structural inequities? Julia urged: "Listen to autistic women. Stop speaking over us, stop trying to help, stop insisting that we are the voiceless in need of a voice, and just listen. Just listen. Because we know what we need and we got this" (addressing the UN on April 2nd, 2018.)

My interest and passion for this project came from years of work witnessing young girls and young women eclipsed by their male classmates who both outnumbered and often (literally) shouted over their perspectives in school programs. I saw girls whose stories were untold and unexplored in school and intervention settings (support groups, social skills groups, autism targeted programming). As I looked to the literature, I found this trend repeated. Most often, when autism is discussed or an autistic person is described, that person is a White male. This project complicates this fixed picture. Bascom's (2018) call to "just listen" has been the mission statement guiding this work.

Chapter I is an overview of the field of autism. I begin with a historical examination of the emergence of autism as a category and the way that autism is framed as a male disorder. I then outline causation frameworks of autism along with the educational and treatment supports for autistic students and adults. While this project specifically focused on women's and girls' experiences, an overall background of the field is essential to frame the deficit ways that all autistics are positioned by positivist research epistemologies which locate the "problem" of autism in the autistic body—a body that has been presumed to be White and male. This narrative inquiry project highlights the stories of autistic women, pushes against these positivist framings,

and centers autistic women's experiences of schooling with the hope that schools can be reimagined to prioritize their experiences, interests, and particular perspectives.

Background: The Emergence of the Category of Autism

Child psychiatrist Leo Kanner is commonly understood to be the first to describe the category "autism" in his 1943 article "Autistic Disturbances of Affective Contact." The etymology of the word *autism* is Greek: *aut* comes from the Greek word *autos* and means "self," and *ism* implies a "state of condition" (Merriam-Webster, 2018). Kanner borrowed the term from Eugen Bleuler (1908), who used it to describe the self-monitoring traits of schizophrenics (Ashok et al., 2012). An Austrian American doctor working out of Johns Hopkins University, Kanner was deeply invested in solidifying the emergent field of child psychiatry and is now widely viewed as the father of child psychiatry (Blacher & Christensen, 2011; Silberman, 2015). While working in the Johns Hopkins Medical Center, Kanner (1943) noticed a set of "unique" and "fascinating peculiarities" (p. 217) in a handful of his young patients. His first study consisted of 11 cases, eight of whom were male and all of whom were White (Kanner, 1943). Kanner (1943) believed that autism was a rare disorder that was narrowly defined and was present at birth (also see Silberman, 2015). He described his autistic patients as displaying an "extreme aloneness from the very beginning" (Kanner, 1943, pp. 248-249). Autistic girls were considered rare.

Simultaneously in Vienna, Austria, Hans Asperger in 1944 was documenting similar traits in some of his students in the Heilpädagogik Station clinic where he worked. Compared to Kanner (1943) and his narrow definition of autism as a disorder of social impairment and rigid and violent behaviors, Asperger was particularly curious about the range of autistic abilities and

attributes, especially in those individuals whom he described as having "autistic intelligence" (Silberman, 2015).

> It seems that for success in science and art, a dash of autism is essential.... For success, the necessary ingredient may be an ability to turn away from the everyday world. (Hans Asperger in 1944 thesis, as quoted in Silberman, 2015, p. 103)

Asperger, like Kanner, believed that autism was much more common in boys, describing autistic traits as "an extreme variant of male intelligence" (Silberman, 2015). Asperger's name later became attached to the diagnostic label of "Asperger's Syndrome," used to describe highly verbal autistics with "average" intelligence (APA, 1994; Murray, 2012).

Heavily influenced by the work of Kanner (1943), autism was included in a subcategory of childhood schizophrenia in the first edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) in 1952 (APA, 1952). Bruno Bettelheim's work in the 1950s and 1960s looked for causation of autistic symptoms. He believed that the roots of autism were environmentally caused. In his popular book, Bettelheim (1967) described the phenomenon of "refrigerator mothers"—cold and detached mothers who created unstable attachments and ultimately led to autistic symptoms in their children (Jack, 2014; Silberman, 2015). At that time, Bettelheim and Kanner were both still referring to autism interchangeably with childhood schizophrenia, understanding the symptoms to be related to a mental disorder. By the late 1960s, attachment theories were discarded for neuroscientific and genetic approaches to autism research (Treffert, 1970).

In the 3rd edition of the *DSM*, autism was re-categorized as a form of "pervasive developmental disorder" or PDD (APA, 1980) and included specific criteria for diagnosis that indicated lack of interest and responsiveness to people, severe impairment in communication, and "bizarre responses to the environment" (APA, 1980, quoted in Volkmar et al., 1986, p. 190).

In the next edition of the *DSM-IV* (APA, 1994), "Asperger's disorder" was added to the autism diagnosis to describe individuals with high verbal abilities (named after Hans Asperger). This category was often referred to as "high functioning autism" (Mayes et al., 2009). The current *Diagnostic and Statistical Manual of Mental Disorders-V* (*DSM-V*) (2013) has defined autism as a neurodevelopmental disorder, "characterized by persistent deficits in social communication and social interaction…including social reciprocity, nonverbal communicative behaviors used for social interaction, and skills in developing, maintaining, and understanding relationships" (APA, 2013, p. 31). This last edition of the *DSM* expanded autism to be a "spectrum disorder" to connote that autistic individuals exist on a wide spectrum of skills, talents, and challenges, and it removed Asperger Disorder or Asperger Syndrome as a diagnostic category. Another key change to the *DSM-V* came in the re-naming of autism as a "childhood disorder" to a "neurodevelopmental disorder." This distinction made it possible for individuals of all age groups to receive a diagnosis (APA, 2013). *DSM* categories are used in schools to determine eligibility for the category of autism within the Individuals with Disabilities Education Act (IDEA) (Colker, 2013).

While there were shifts in diagnostic categories, girls and women were still being represented as a fraction of the overall autistic population. Kanner's (1943) original study suggested that girls accounted for a small percentage of the population (3 in 11 of the case study children were girls), whereas Asperger (1944) suggested that autistic women did not exist. In the 1990s, it was reported that the girl/boy ratio of autism diagnosis ranged from 15:1 to 13:1 (Fombone, 2009). The most recent studies have suggested that the ratio has narrowed to 4 boys to 1 girl (Maenner et al., 2020). Overall, it is still commonly accepted that boys more frequently have a diagnosis of autism than girls.

The changes to the *DSM* criteria reflect deep philosophical changes in theories of autism causation. In the 1950s and 1960s, when autism was believed to be a form of childhood schizophrenia (APA, 1952), there was a deep belief in family environmental factors, mainly parenting styles. Starting in the 1970s, research shifted from looking at family parenting styles to genetic and neurodevelopmental causation (Treffert, 1970). Large-scale epidemiology studies examined potential "risk factors" of autism, such as older parental age (Croen et al., 2007; Durkin et al., 2008; Reichenberg et al., 2006). Additionally, Ozonoff et al. (2011) found that siblings of autistics had a 20% rate of also receiving an autism diagnosis. A large-scale Finnish study found that siblings of autistic children were 2.5 times more likely to have a condition such as autism, ADHD, intellectual disability, or learning disorder (Jokiranta-Olkoniemi et al., 2016). Twin studies reported high rates of autism among identical twins (Anderson, 2012; Bell & Spector, 2011; Folstein & Rutter, 1977), with one study claiming that the correlation was as high as 55% (Hallmayer et al., 2011).

The last 50 years of autism research has also produced many theories that have later been debunked as fake science. Many of these theories pointed to environmental toxins as being a trigger for the rise in autism diagnoses. Perhaps the most widespread of these theories came from British gastroenterologist Andrew Wakefield (1998), who claimed that the MMR vaccine, specifically the compound thimerosal, caused autism (Silberman, 2015). After it was revealed that Wakefield had falsified data and patient information, his study was discredited and he lost his medical license (Taylor et al., 1999). However, the myth around vaccines and autism is still echoing in the public consciousness. Genetic studies have most recently identified 91 genes that are linked with autism (Stressman et al., 2017), although this kind of gene research is in its infancy. The current field of autism research is still in many ways a field of unknowns. Dr. Stuart

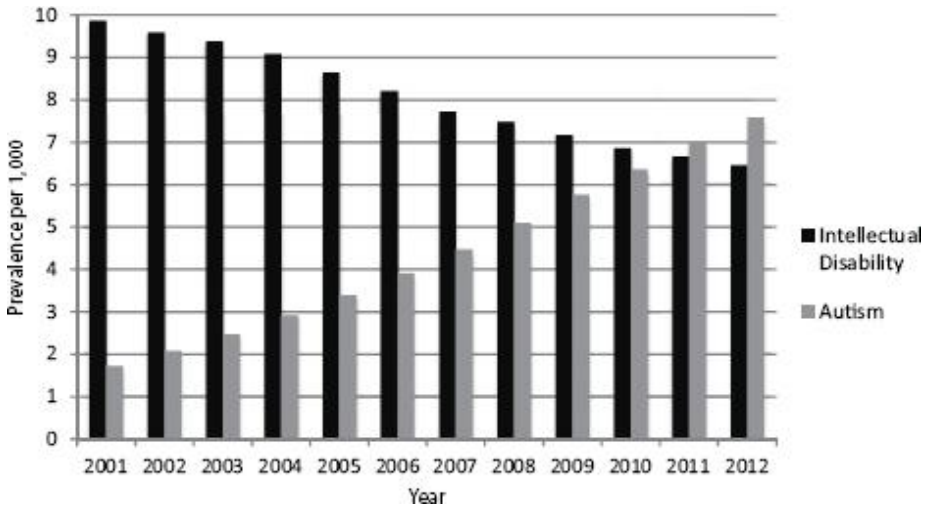
Murray (2012), a medical humanities professor, said it best: "The central fact about autism with which we should probably start is that we don't know very much about it at all" (p. 1).

What we do know is that rates of autism have been increasing over the past two decades. Currently, 3.5 million Americans have an autism diagnosis (Buescher et al., 2014). In the 1960s and 1970s, an average of 2 to 4 cases of autism out of 10,000 children was reported (Lotter, 1966; Treffert, 1970). These rates look much different today. The most current diagnostic rates from the CDC reported that among 8-year-olds in the United States, 1 in 54 children are diagnosed with autism. This is a 15% increase from 2012, when the rates were 1 in 68 children (Maenner et al., 2020). Diagnostic rates for girls have shifted slightly. In 2012, boys were 4.5 times more likely to receive a diagnosis, whereas now boys are 4 times more likely to receive a diagnosis of autism than girls (Maenner et al., 2020).

Increased rates of autism diagnosis have led some researchers, doctors, parent advocates, lobbyists, and media outlets to label this an epidemic. These claims have made it into official government hearings; "What we have is an epidemic," explained Chairman of the Committee on Oversight and Government Reform Congressman Darell Issa, during an official committee hearing on autism research funding in 2012. Public health campaigns advertised "warning signs" of autism to parents of young children and circulated posters to pediatricians' offices and early childhood education centers (Daniel et al., 2009; Durkin et al., 2008; Grether et al., 2009; Rice et al., 2012). Other researchers, however, have dismissed the "epidemic" label and instead attributed autistic population increases to expansions of Autism Spectrum Disorder (ASD) diagnostic criteria from Kanner's (1943) narrow definition to a more expansive definition in the *DSM-V* (Fombone, 2009; Lotter; 1966; Rice et al., 2007). Still others have claimed that autism rates have increased as other disability categories have decreased; thus, the increase in autism

rates is really a reclassification of other disability categories such as intellectual disability (see Figure 1; Polyak et al., 2015). Steve Silberman (2015) argued that the concept of an "autism epidemic" is a farce: "Whatever autism is, it is not a unique product of modern civilization. It is a strange gift from our deep past passed down through millions of years of evolution" (p. 470). Simply put, many autistics see the rise in numbers as recognition of an existing and long-standing community.

Figure 1. *Rate of ASD and Intellectual Disability Category*



Source: U.S. Department of Education (2014)

Who is considered and counted as part of the autistic community depends heavily on gender and racial categories. There are significant gender and racial disparities in autism diagnosis. The most current CDC rates have measured the male-to-female ratio of autism diagnosis (at age 8) to be 4:1 (Maenner et al., 2020). In addition to gender, a diagnosis of autism is influenced by race. While there is an overrepresentation of students of color in special education (Dunn, 1968; Harry & Klinger, 2006; Sullivan & Bal, 2013), a reverse trend is occurring for autistic children. White students account for 67% of the autistic population (Colker, 2013). Furthermore, students of color who are diagnosed with autism more often receive

the diagnosis at a much older age. The CDC reported that although Hispanic students were identified with developmental delays, full evaluations were on average postponed by 18-24 months, as compared to their White counterparts. These delays meant that Hispanic students did not receive crucial interventions at earlier stages of development (Christensen et al., 2012). Currently, the CDC does not mention the diagnostic age differences between girls and boys. A 2012 study found that girls were less likely to meet the criteria for an autism diagnosis than their male peers, even though girls displayed high levels of "autistic-like" behaviors (Dworzynski et al., 2012, p. 796). The theories around gender disparity are explored further in Chapter II.

One major reason why autism diagnosis increased in the 1990s was that it was included as a disability category under the IDEA (Gernsbacher et al., 2005). Although the Education for All Handicapped Children Act (EHCA) in 1975 procured legal rights for all disabled students (Colker, 2013), it was not until its reauthorization as the IDEA in 1990 that autistic students were specifically included under these legal protections. The IDEA mandates that students receive a free and appropriate education (FAPE) from ages 3 to 21, that students be educated in the least restrictive setting, and that students and families collaboratively draft an Individual Education Plan (IEP) with the school staff (Colker, 2013). The IEP outlines what supports, therapies, and goals a student would meet and require during that school year (Yell & Crockett, 2011). Common supports for autistic students include occupational therapy, physical therapy, speech therapy, counseling and mental health services, special education services, and/or access to assistive technology in order to access curriculum (Wei et al., 2013). The IEP is a legal contract between the school and the families.

By and large, autistic students attend public school programs and spend the majority of their school day in general education settings. Table 1 below, compiled by the National Center

for Education Statistics (U.S. Department of Education, 2017), compares the types of school environments in which autistic students learn as compared to students in all other disability categories. However, when compared to all students with disabilities, autistic students are twice as likely to attend "separate schools for students with disabilities" and are far more likely to spend less than 40% of their school day in general education classrooms (NCES, 2017).

Table 1. *Autism and Schooling*

Percentage distribution of students 6 to 21 years old served under Individuals with Disabilities Education Act (IDEA), Part B, by educational environment and type of disability: Fall 2014							
Type of Disability	**All Environments**	**Regular School, Time Inside General Class**			**Separate school for Students with Disabilities**	**Separate Residential Facility**	**Parentally Placed in Regular Private Schools**
		Less than 40%	**40–79%**	**80% or more**			
All students with disabilities	**100.0**	**13.7**	**18.9**	**62.2**	**2.9**	**0.3**	**1.3**
Autism	100.0	32.9	18.1	39.9	7.3	0.4	1.1

Source: NCES, U.S. Department of Education (2017)

Autistic students often receive either specialized supports in the classroom or individualized instruction out of the classroom. These specialized services are often referred to as treatment interventions (Murray, 2012; Silberman, 2015). Treatment interventions for autistic students are numerous and include general interventions that are commonly used in school and clinic settings and biomedical interventions that are overseen by doctors or implemented by families. One of the first interventions designed for autistic children, and still the most used intervention to date in both schools and private clinics, is Applied Behavior Analysis (ABA), which was developed by clinical psychologist Dr. Ivar Lovaas (1987). Lovaas rejected a psychodynamic understanding of autism that looked at family and relationships as the foundation of treatment (Bettelheim, 1967) and instead drew from the behavioral psychologist B.F. Skinner and his work of "operational conditioning" with pigeons and rats (Skinner, 1953). Lovaas (1987)

believed autism to be a disorder of motivation and therefore developed an intervention that used rewards and punishments to elicit targeted behavioral outcomes in children. Success, for Lovaas (1987), meant "recovery" from autism measured by average IQ scores (p. 8).

ABA and other behavioral interventions are the most commonly used intervention methodology in school and clinic settings for autistic children (Devita-Raeburn, 2016). Most autistics have had experience with ABA or other behavioralist interventions (e.g., discrete trial training, Lovaas model, Intensive Behavior Treatment) (Broderick & Ne'eman, 2008; Murray, 2012; Yergeau, 2018). In recent years, behavior interventions, specifically ABA, have been increasingly criticized by the autistic community as perpetuating forms of abuse under the label of treatment (Gardiner, 2017; Sequenzia, 2015). One major critique is that ABA aims to "cure" autism by making autistics "indistinguishable" from their peers (Lovaas, 1987, p. 8). Harsh and painful punishments have been inflicted on autistic children under the umbrella of ABA intervention (Moser & Grant, 1965; Yergeau, 2018). Lovaas used shock treatment in his early studies (Moser & Grant, 1965). While this has become less common, it is still used in school settings that service autistic youth, perhaps most notably the Judge Rotenberg Education Center in Massachusetts, which receives state funding (National Council on Disability, 2014).

Another type of intervention is the developmental or constructivist methodological approach. These methodologies pull heavily from the child psychology field (Bowlby, 1969; Lester et al., 1985). A developmental approach includes the DIR Floortime model (Wieder & Greenspan, 2003), the PLAY project (Solomon et al., 2007), and the SCERTS model (Prizant et al., 2003). Whereas ABA uses external reinforcement to encourage skill development (i.e., rewards, tokens, or praise) (Lovaas, 1987; Scheithauer et al., 2020), developmental approaches incorporate students' interests into play and therapy sessions to increase communication, motor

developmental goals, and social interaction (Wieder & Greenspan, 2003). Although many in the autism community view the developmental models as being less harmful and more respectful as compared to ABA (Gardiner via The Autistic Self Advocacy Network, 2017), these developmental models still use typical child development as the model of "healthy" development; thus, the autistic child is still understood to be abnormal. A more in-depth review of behavioral school-based and developmental home-based intervention studies is covered in Chapter II.

Common therapeutic interventions for autistic people include speech therapy, occupational therapy, physical therapy, and various mental health supports such as counseling, music therapy, art therapy, and social work services (Murray, 2012; Silberman, 2015). These interventions are commonly provided in school settings or after school in private clinical settings. Many autistic individuals have a co-occurring diagnosis, specifically seizures, psychiatric disorders, and gastrointestinal disorders, that may require medical treatments and various pharmaceutical interventions (Doshi-Velez et al., 2014). Autistic women have reported high rates of anxiety, depression, and anorexia (Hendrickx, 2015). There are no medications specifically designed to "treat" autistic patients. Both inside and on the fringes of the medical establishment lie a host of other biomedical "interventions" for autism. While many autistics have gastrointestinal issues, there are a wide variety of responses to treat these gut issues, including various diets (DAN, gluten-free, casein-free, dairy-free). Other approaches have less mainstream support, including hyperbaric chamber sessions (high oxygen treatments); chelation (removal of lead, mercury, and iron build-up in the blood stream); intravenous treatments; and microbiome cleanses (Silberman, 2015). Many of these treatments range from uncomfortable (hyperbaric chamber) and/or inconvenient (diet interventions) to painful and invasive (chelation).

Education and therapeutic supports for autistic students vary by state; however, there are far more supports for autistic students than autistic adults. Student supports are funded through the state and city education systems until they are 21 years old. After that, autistic adults receive a greatly reduced amount of funding through Social Security and/or Medicaid (Howlin et al., 2004; Shattuck et al., 2012). Parents of autistic adults commonly refer to this transition as "falling off the cliff" (Hanley-Maxwell et al., 1995). Over the next 10 years, 500,000 autistic students (50,000 per year) will age out of school-based programs (Roux et al., 2017).

There are significant barriers of access for autistic adults, including employment, postsecondary education, and housing. The National Longitudinal Transition Study (NLTS2), a large-scale national study that examines the outcomes of high school students in special education who are transitioning out of the school system, reported that 19% of young autistic adults lived away from their parents, 58% were unemployed, and only 36% of autistic students ages 20-25 had enrolled in postsecondary education or other forms of advanced training (Newman et al., 2011; U.S. Department of Health and Human Services, 2017). Additionally, autistic adults have serious health risks related to stress, mental health, inadequate health care, depression, and other neurological conditions such as epilepsy (Hirvikoski et al., 2015; Newman et al., 2011). The average life expectancy for autistics is 36 years, a strikingly short life span as compared to the general population with an average life expectancy of 72 (Guan & Guohua, 2017). Autistic women may be particularly vulnerable to suicidal ideation. One theory is that because autistic women are often diagnosed later in life, their symptoms go untreated (Hirvikoski et al., 2015).

Autistic adulthood is made difficult by a lack of support services and by institutionalized ableism, which affects employment opportunities and housing access. Ableism is the structural

and personal bias against disability and disabled people; "ableism refers to the ideological hyperevaluation of ableness and the ways in which such norms of abled and disabled identity are given force in law, social policy, and cultural values" (Campbell, 2015, p. 13). Regardless of, and perhaps partly because of, these barriers, autistic communities and autistic culture are strong and vibrant. Increasingly, over the last several decades, autistics have taken leadership roles in disability rights movements. Jim Sinclair, Kathy Lissner Grant, and Donna Williams founded the Autism Network International (ANI) in 1992 as the first major organization run by and for autistic people. Sinclair (2010) explained why the group formed: "A few of us had also met each other in person at autism conferences, run by and for NT [neurotypical[3]] parents and professionals. But typical autism conferences do not tend to be very good places for autistic people to connect meaningfully with each other" (n.p.). In alignment with the disability rights motto, "Nothing about us without us" (Charlton, 1992), ANI took a strong stand against a cure culture of autism and advocated for autistics to be more central to conversations around programming and supports. Sinclair (1993) took the stage at the International Conference on Autism in Toronto and demanded that parents "Don't Mourn for Us." Instead, he pushed for parents and researchers to understand that "Autism is a way of being…. Therefore, when parents say, I wish my child did not have autism, what they're really saying is, I wish the autistic child I have did not exist." Framing autism as a culture rather than a disease or disorder has become foundational to the neurodiverse movement (Broderick & Ne'eman, 2008).

Under the umbrella of neurodiversity, neurological differences like autism are viewed as natural variants of neurological differences rather than a deficit to be cured. Since the early

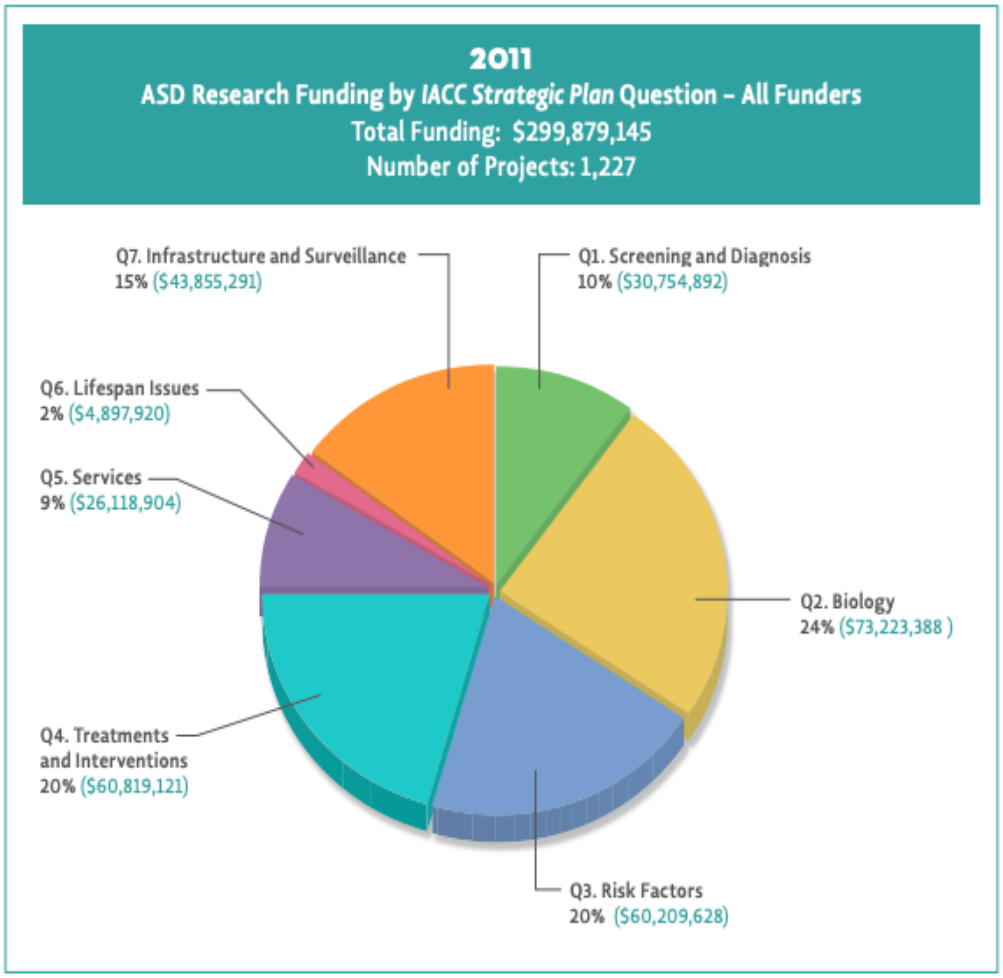
[3] Neurotypical or NT refers to non-autistics and is covered in greater detail later in the chapter.

1990s, self-advocacy and autistic community organizing has strengthened. The Autism Self-Advocacy Network (ASAN) advocates for autistic rights within the larger disability community and specifically examines issues of intersectionality with other disability groups. Additionally, the Autistic Women and Non-Binary Network (AWN) was formed specifically to help support the unique issues of women and non-binary autistics because those issues were being unexplored in other autistic communities. Leaders from these organizations include Lydia X.Z. Brown (2017), Ari Ne'eman (cofounder of ASAN), Morenike Giwa Onaiwu (board member of AWN), and Julia Bascom (director of ASAN). Additionally, online communities are powerful spaces for autistic communion and organization. In Chapter II, the scholarship and voices of these activists are further explored.

However vibrant the autistic community, autism research does not often include the perspectives and expertise of autistics. The majority of autism research comes from the psychological and epidemiology fields and examines causation and the biological factors of autism. The Office of Autism Research Coordination (OARC, 2016) examined autism research funding in 2011 and 2012. This review included both federal funding and other agencies like the National Institutes of Health (NIH), the National Science Foundation (NSF), and large private funders such as Autism Speaks. In 2011, $300 million dollars were dedicated to autism research, and of it, only 7% went to researching services for autistic people, while only 1% of research addressed the needs of autistic people. This is compared to research that examined risk factors (17%), biological factors of autism (30%), and treatments (19%). In the category of treatment,

only 10% of funding examined the effectiveness of community-based treatment options (see Figure 2), whereas a vast majority examined behavioral approaches such as ABA. In Chapter II, I go into more detail about the kinds of research studies that currently dominate the field and the ways in which autistic women are both underrepresented in populations of studies as well as issues specific to autistic women are going unexplored in the research.

Figure 2. *Types of ASD Research Studies in 2011*



Source: Office of Autism Research Coordination, 2016, p. 23

Statement of the Problem

The field of autism research is disproportionately focused on autism causation, specifically the biology of autism. This research is framed from an epidemiological perspective. Epidemiology is the study of disease and, more specifically, the "control of disease" (World Health Organization [WHO], 2018). Coming from an epidemiological epistemology, autism is treated as a kind of contagion or disease, an issue to be explored, understood, solved, and ultimately cured. There is little emphasis on, and little funding for, research that explores the lived experiences of autistics or the ways in which programs designed for autistics improve their lives. Instead, the lion's share of research money is spent on prevention and cure. Research is *done on* autistic people and, more specifically, autistic bodies. Treatments are examined in terms of percentage of improvements on standardized norm-sampled assessments such as IQ tests and Autism Rating Scales. Success is measured in degrees towards normalcy, degrees away from autism, and closer to "the norm." Scholar and autism advocate Ari Ne'eman wrote, "In the discussion about autism, autistic people are generally off-stage characters, referred to constantly, invoked with great passion and pomp, but not fit to offer any lines of actual dialogue" (Broderick & Ne'eman, 2008, p. 471). Autistics are sidelined in conversations around their own lives and futures.

The overall field of autism research draws heavily on positivist epistemologies (Broderick, 2011; Murray, 2012; Yergeau, 2018), and it is also overwhelmingly focused on male autistic experiences. CDC statistics have shown a huge gender imbalance in diagnosis (4 males to 1 female); however, those statistics are based on children under the age of 8 (Maenner et al., 2020). These numbers underreport and greatly misrepresent the number of autistic women. Autistic women often share that if they did not receive a diagnosis of autism until well into their

late teens or adulthood. Sarah Hendrickx (2015), an autism researcher and educator, was working professionally in the field of autism for 5 years before she received a diagnosis at the age of 43. She noted:

> There are plenty of women with autism, but we just hide it better, make sense of it differently or present in a way that slips under the radar of those looking for classic (male) indicators derived from the (almost) exclusively male research (or at least research that does not differentiate according to gender). (p. 15)

Instead, women are often incorrectly diagnosed with highly gendered mental health issues such as anxiety, eating disorders, Bipolar Disorder, and depression (Hendrickx, 2015; Kim, 2013). The gendered nature of autism has gone woefully under-researched (Hendrickx, 2015) and autism has been framed as a disability of men. Assumptions around the role of biological and genetic influences have led researchers like Simon Baron-Cohen (2003) to frame autism as an "extreme male brain." This is not viewed as fringe research; rather, it reflects mainstream views as "scientifically sound" and commonsensical.

There is little documentation regarding the age at which women receive a diagnosis as compared to men. Current autism research draws participant pools that are representative of the community; however, when the community is narrowly defined by CDC ratios that do not count individuals who are diagnosed later in life, the ratios disproportionally skew male and, thus, reinscribe the false notion that autism is primarily a male disorder and identity. Kevin Pelphrey, a researcher at the Yale University Child Study Center and father of an autistic girl, explained, "Everything we thought was true of autism seems to only be true for boys" (Szalavitz, 2016). Without research that specifically addresses the lived experiences of autistic women, schooling supports and programs designed for autistic people and youth are going to predominantly reflect priorities for male autistics. This lack of research points to a gap in the field.

Research on autism and schooling reflects a behaviorist perspective wherein autistic behaviors are counted and tallied, and interventions are deemed as successful when autistic behaviors are lessened and IQ scores are increased. Again, these research studies have either ignored gender altogether or underrepresented girls in their data samples. There is simply not enough research that explores the lived experiences of autistic women and girls in school. Autistic women's autobiographies (Hendrickx, 2015; Yergeau, 2018) have described complex social dynamics and feelings of being erased, ignored, and misunderstood during their childhood schooling experiences. None of these experiences can be captured using standardized tests.

Statement of Purpose

The purpose of this study was to explore the stories that autistic women share about their past educational histories, particularly the role that their gender and autism identities played in shaping their school relationships. Working narratively through multimodal data collection, I privileged their sense making and the form of expression and communication they preferred. My hope is that through their stories, autistic women's expertise will be honored as essential to all conversations about schooling interventions for autistic youth. By exclusively focusing on women, I challenge the myth of autism as a male category and challenge a positivist autism research approach that ignores gender altogether.

Rationale

My research was framed by a Disability Studies (DS) theoretical stance that forefronts the experiences of disabled people (Biklen, 2005). This centering of autistic experiences is key to this project and reflects a major gap in the field of autism at large. A DS framework fundamentally challenges the medical model of disability that locates the source of inequity in the body of the disabled person (Baglieri et al., 2011; Siebers, 2008). DS views disability as a

social construct; it is the environment that creates inequities for disabled individuals, not the disabled body. Additionally, I looked at the way in which DS overlaps and is enhanced by other intersectional theoretical models, including feminist theory, DisCrit, and queer theory. These theoretical frameworks unpack the notion of deviance as compared to a mythical "normate," i.e., the English-speaking, White, male, heterosexual, able-bodied person (McRuer, 2006).

Queer theory is particularly generative for this project as it challenges binary thinking—homo/hetero, male/female, deviant/holy (Butler, 1993; Jogese, 1996)—and allows for messy categories and fuzzy edges of identity. I am more interested in the idea of "queering" and how concepts from queer theory can open up possibilities for non-linear narratives that may be more authentic to my participants' autistic ways of knowing. "To queer" is to challenge, to disrupt, to complicate: "Queer must insist on disturbing, on queering, social organization as such—on disturbing, therefore, and on queering *ourselves* and our investment in such organization. For queerness can never define an identity; it can only ever disturb one" (Edelman, 2004, p. 17). A research project grounded in an intersectional framing of disability studies with influences from feminist theory, DisCrit, and queer theory afforded me the critical space to ask challenging questions: How do female autistics experience autism? How do they describe their experiences? Using queer theory, I interrogated the very categories that I have had to take up for this study. What does it mean to be female? What does it mean to be an autistic woman? What is gained/ lost in ascribing to the category of autistics? How do schooling practices confine or expand these notions of identity?

This narrative inquiry project made space for people's own constructed meanings. This was particularly crucial to center autistic ways of knowing and communicating, which may extend beyond a strict verbal interview format. Narrative inquiry investigates the lived

experiences of individuals (Clandinin, 2013) and examines the ways in which individuals make sense of their worlds. Narrative inquiry privileges individuals' own construction of their identities. This project did not aim to reveal universal "truths" about autistic young women's experiences. Ultimately "autism, like any topic, is not knowable in a definitively objective sense" (Biklen, 2005, p. 3). Instead, I explored the nuanced ways that these particular participants made sense of their lives and particularly their schooling experiences to complicate the stock story of a White male autistic student (Mitchell & Snyder, 2013).

Research Questions

How do autistic women author their schooling experiences?

1. What do autistic women share about their schooling experiences?
    a. What experiences do they identify as supportive and/or challenging? Why?
    b. What is the significance of intervention in their school lives?
2. How do autistic women express their identities?
    a. What understandings of disability and normalcy do they disclose?
    b. How do they express their gender identity?
3. How are relationships made significant in autistic women's lives?
    a. What kinds of relationships with staff and peers do they disclose?
    b. How do they navigate and define their relationships?

Significance

Schooling interventions, social supports, and special interest groups that are designed to support autistic students are built on the assumption that autistics are male. The history of autism research comes from a positivist and medicalized epistemology that locates the "problem" of autism in the autistic body. Autistics are rarely included as knowledge producers in

conversations, policies, and schooling practices around autism. My study centered autistic women. They are not placed on the side, they are not a small minority, and their gender and race are not ignored. Centering autistic women's experiences challenges the notion of autism as a White male disability and encourages more inclusive programming and educational approaches that plan for and with autistic women and girls, not as periphery but as central members of the community.

Use of Terms

Throughout this research, I refer to my participants and the community as *autistic* or *autistic woman/man/non-binary person* rather than person with autism. This is a choice I made. Historically, psychologists and special educators have advocated for person-first language and have favored "person with autism." The rationale is that their disability label should not define a person (APA, 2013; Dunn & Andrews, 2015).

Over the last 10 years, many autistic people (Shore, 2003), disability activists and scholars (Brown et al., 2017; Giwa Onaiwu, 2017), and disability studies scholars (Bruggemann, 2013; Davis, 2013; Goodley, 2011; Kafer, 2013) have pushed against this nomenclature and instead call for the term *autistics*. They argued that autism is an identity category and an aspect of diversity (Dunn & Hammer, 2014). A person does not "have gayness" and they are not "a person with Asianess," and so autism is not external to identity. Therefore, the preferred term by many self-advocates is *autistic(s)*. The cartoon drawing below (Figure 3) by Terry (no last name) poignantly illustrates this point (overexplainingautistic.tumblr.com). The first panel shows autism as a dog, something that accompanies the person: "Come on Autism, time for a walk." The second frame shows a person with a neurodiversity symbol (∞) on their shirt illustrating an identity-first preference.

Figure 3. *Illustrating the Difference between Person-first and Identity-first Language*

Source: overexplainingautistic.tumblr.com

Disability Studies scholar and activist Lydia X.Z. Brown (2011) explained the history of the language debate in their blog, *Autistic Hoya*. They posited that person-first language (i.e., women with autism) comes from a medical epistemology. For example, a cancer patient is described as a "person with cancer" instead of a "cancerous patient" (Brown, 2011); however, this line of logic does not fit with the autistic identity because autism is not a disease.

> Ultimately, what we are saying when we say "person with autism" is that the person would be better off if not Autistic, and that it would have been better if he or she had been born typical. We suppress the individual's identity as an Autistic person because we are saying that autism is something inherently bad like a disease. Yet, when we say "Autistic person," we recognize, affirm, and validate an individual's identity as an Autistic person. We recognize the value and worth of that individual as an Autistic person—that being Autistic is not a condition absolutely irreconcilable with regarding people as inherently valuable and worth something. (Brown, 2011, n.p.)

For this reason, I used *autistic(s)* throughout the piece to remain in epistemological alignment with the autistic community.

Non-autistic people are often referred to as "neurotypical" or "NTs" (Silberman, 2015; Sinclair, 1993); however, I used the word "allistic" or non-autistic (Zefram, 2003) as it avoids

the value marker of normalcy and typicality which positions autism as atypical. Autistic blogger Andrew Main Zefram invented the term as a counterpoint to the word autism. *Auto* (autism) comes from the Greek word for "self," whereas *allos* (allistic) comes from the Greek word for "other" (Merriam-Webster, 2018).

There are other times when I use the terminology *students with disabilities*, when I am referring to a group of students who have various different disability identities. Whereas "autistic" is a very clear preference within the autistic community, there are other disability identities that do not prefer person-first language. Disability activist Emily Landau (2015) explained, "the same concepts do not apply when it comes to the use of a term strictly for its medical definition. For instance, is never ok to say, 'cerebral palsy person'…language is never 'one size fits all'" (n.p.).

Chapter II: REVIEW OF LITERATURE

Disability Studies (DS) is an intersectional lens from which to better understand the field of autism research. First, I explore the underlying assumptions of DS as well as intersectional post-structural approaches to unpacking deviance, difference, and the messy and intersecting edges of identity and disability. Interwoven into my theoretical review are the stories, quotes, and academic contributions of autistic writers and activists, specifically autistic women and autistic non-binary people. I then outline the predominant research positions in Autism Spectrum Disorder (ASD) research, the majority of which are deeply grounded in a positivist medicalized epistemology that positions autism as a fundamental "lack" (Yergeau, 2018, p. 7). Although my study focused on schooling, the majority of autism research has not included schools; therefore, much of the review is a mapping of the autism research field at large. The last section covers research more specifically related to schooling.

The larger context is crucial to understand because these medicalized values and assumptions about autism and autistics have become common sense. They form the backdrop for schooling interventions as well as the pushback from DS in Education research against these deficit framings of autistic students. As a DS researcher working from an intersectional analysis of identity, I must account for the ways in which the autism field has been framed so that I can then push against it in my own research design.

Disability Studies

Disability Studies (DS) challenges notions of disability as a form of lack or "personal tragedy" and instead understands disability as an expected variation of the human experience (Goodley, 2011, p. xi; Zola, 1989). DS is an interdisciplinary field that works at the intersections of the social sciences (Goffman, 1961; Zola, 1982); literature (Adams, 2015; Berube, 1996;

Davis, 2013; Garland-Thomson, 1997; Mitchell & Snyder, 2013); philosophy (McRuer, 2006, Siebers, 2008; Simplican, 2015); history (Baynton, 2001; Davis, 2015); education (Baglieri et al., 2011; Biklen & Burke, 2006; Erevelles, 2006); and the arts (Linton, 1998).

DS as an academic field grew out of the need and interest to "think critically about disability, a juncture that can serve both academic discourse and social change" (Linton, 1998, p. 1). Meaningful change would only occur when disabled people were included as central stakeholders in conversations around disability justice; therefore, "Not about us without us" became a rallying cry across disability justice movements (Charlton, 1992). This tradition of centering disabled voices is the core of the academic field of DS. Many DS scholars identify as either disabled (Garland-Thomson, 1997; Kafer, 2013; Linton, 1998; Piepzna-Samarasinha, 2018; Siebers, 2008), or as a parent/family member of (Adams, 2013; Berube, 1996; Davis, 2015; Ferguson, 2001; Wong, 2002) or a close ally to the disabled community (Biklen, 2005; Broderick, 2011). Research that employs a DS perspective centers disabled perspectives, knowledges, and stories. Researchers working from a DS lens collaborate with participants rather than position themselves as experts and their participants as subjects.

The emergence of DS as an academic field grew out of the disability rights movement of the 1960s and 1970s, which demanded more legal protections and equal access to government services, including public transportation, public accommodations, and accommodations in the workplace (Mezey, 2005). These rights were legally established with the passage of the Americans with Disabilities Act (ADA) in 1990. Although the ADA was passed more than 25 years ago, in some ways little has changed for disability rights. For example, the rates of employment for disabled people have continued to decline (Maroto, 2015). Maroto (2015) argued that the ADA did little to alter the deeply held and dangerous stereotypes maintained by

employers that disabled people are incapable and weak (Russell, 2002). DS scholars have argued that these kinds of stereotypes were born from the medical model of disability.

Medical and Social Model of Disability

DS scholars challenge the medical or individual model of disability that is most often taken up by the medical establishment (physicians, psychiatrists, epidemiologists). Central to the medical model is locating the "problem" within the body of the disabled person (Barnes, 1991; Oliver & Barnes, 1996). Because the "problem" is presumed to be the disabled person, the logical solution is a cure. Cure culture creates an imbalance between professionals and the disabled community wherein the professionals are experts and adopt a paternalistic relationship towards disabled people (Oliver, 1990; Oliver & Barnes, 1996). Conversely, the social or sociopolitical model of disability locates the "problem" not within the body of the disabled person, but rather in a society that constructs and labels a disabled body as less than (Barnes, 1991; Hahn, 1988; Oliver, 1990). Born of the British disability rights movement, the social model frames disability as socially constructed, needing to be understood from a "social, cultural, and historical context" (Ferguson & Nussbaum, 2012, p. 73). For example, a wheelchair user's disability is created because of societal inequities, not because of their individual differences (Erevelles, 2006; Siebers, 2008). It is the playground without a ramp or the curb without a cut that creates inequity of access, not the wheelchair user.

Understanding the difference between impairment and disability is at the heart of the social model of disability. Impairment is "individual and private," whereas disability is "structural and public" (Shakespeare, 2013, p. 216). A blind person has a visual impairment, but a disability is created by a society which privileges written text without audio transcriptions or Braille alternatives. The individual model of disability is far too limiting and fails to

acknowledge that "barrier free environments [are] likely to benefit not just those with a mobility impairment but other groups as well (e.g., mothers with prams and pushchairs, porters with trolleys)" (Oliver, 2004, p. 21). In the case of autism, the *DSM-V* stipulated that it is a disorder with impairments in three different areas: social integration, communication, and an increase in repetitive behavior (APA, 2013). From the perspective of the social model, the disability of autism is created by a society that does not account for impairments. For autistics, this may translate into environments that do not understand or account for various communication styles (i.e., augmentative communication, picture communication systems, gestures, or movements).

Complex Embodiment and the Political/Relational Model of Disability

Some DS scholars have argued that the social model of disability flattens the complexity of the disabled experience and underplays the role of impairment in the everyday lives of disabled people (Crow, 1996; French, 1993). Liz Crow (1996) criticized the social model for failing to acknowledge the role of pain: "Many of us remain frustrated and disheartened by pain, fatigue, chronic illness, including the way they prevent us from realizing our potential or rallying fully against disability (our experience of exclusion and discrimination)" (p. 4). The social model creates a too clean black-and-white binary understanding of disability. Shakespeare and Watson (2002) described this succinctly: "It sounds better to say, 'people are disabled by society, not their bodies' than to say, 'people are disabled by society as well as their bodies'" (p. 10).

Rather than a pure social model, Siebers (2008) framed disability as a "complex embodiment", which challenges Western constructions of a binary mind/body dualism wherein the mind has rational control over the body (Wilkerson, 2015). Feminist theorists offered an embodiment notion of gender: "bodies, then, are not born; they are made" (Haraway, 1999, p. 207). The male body is *made* to be average, typical, or neutral; therefore, deviations from this

male body are constructed as abnormal, "irrational" and feminine (i.e., menstruation, childbirth, menopause) (Wilkerson, 2015, p. 68). Understanding disability through the lens of complex embodiment opens up new opportunities to challenge seemingly stable categories.

Building from queer and feminist theory, Alison Kafer (2013) rejected the individual/ medical model of disability, though she was also wary of a full social model because it undervalues the importance of medical interventions and treatments for the improved lives of disabled people. Kafer offered a messier hybrid construction of disability that she named the "political/relational model."

> It [political/relational model] recognizes instead that medical representations, diagnoses, and treatments of bodily variation are imbued with ideological biases about what constitutes normalcy and deviation. In doing, it recognizes the possibility of simultaneously desiring to be cured of chronic pain and to be identified and allied with disabled people. I want to make room for people to acknowledge—even mourn—a change in form or function while also acknowledging that such changes cannot be understood apart from the context in which they occur. (p. 6)

Kafer's queering of the social model creates space for individual responses to impairment while at the same time honoring and celebrating disability culture and activism. Siebers' (2016) complex embodiment and Kafer's (2013) political/relational models of disability create pockets of possibility for complex storying of disability and impairment experiences.

Notions of embodiment are crucial for unpacking DS scholar Melanie Yergeau's (2018) authoring of her autistic body:

> I very clearly remember the long process of being toilet trained. These memories starkly diverge from the ways in which other people typically narrate their own experiences with learning to use the bathroom—which is to say, other people typically don't. By contrast, I do not remember learning to read. Decoding symbols felt less effortful, even as a toddler, but decoding my body—decoding sensations, recognizing which tightness meant which function, rehearsing the order of bodily motions required to use a toilet—these things long eluded me. (p. 6)

Yergeau went on to explain the ways in which teachers struggled to hold these two seemingly conflicting notions together: How could a student excel academically and struggle with toilet training? Yergeau's mother had to push to keep her daughter in general education classrooms as teachers and administration did not know how to accommodate and make sense of Yergeau's differences.

Disability Identity

Through the lens of a social model of disability, disability is understood to be a minority category that experiences discrimination in ways similar to other minority groups that have been unfairly and structurally disadvantaged (Rodas, 2015; Siebers, 2008), suggesting a "shared experience of oppression" (Straus, 2013, p. 466). Part of the importance of claiming disability as an identity category comes from a need to be acknowledged openly. Carlson (2015) outlined the history of disability in the United States that has been marked by a history of seclusion (lack of accessible public spaces), segregation (institutionalization), and separation (in separate education settings). Scholar and disability activist Simi Linton (1998) outlined the need to be acknowledged as a community:

> Disabled people, and I will immediately identify myself as one, are a group only recently entering everyday civic life. A host of factors have typically screened us from public view. We have been hidden—whether in the institutions that have confined us, the attics and basements that sheltered our family's shame, the "special" schools and classrooms designed to solve the problems we are thought to represent, or riding in segregated transportation, those "invalid" coaches, that shuttle disabled people from one of these venues to another. The public has gotten so used to these screens that as we are now emerging, upping the ante on the demands for a truly inclusive society, we disrupt the social order. (p. 3)

DS scholars have argued that the abled body is a construction. Most individuals who are disabled were not born with a disability. The U.S. Census (2010) reported that 19% of the population said they had a disability, but only 1% were born with a disability. Disability is a

porous category that can affect individuals across the lifespan: “disability is the one identity category that all people will embody if they live long enough” (McRuer, 2006, p. 30). Ablebodiedness is a temporary state referred to within the DS community as “temporarily able bodied” (TAB) (Adams et al., 2015; Garland-Thomson, 1997).

Disability as identity is a constantly evolving and contested concept within the DS scholarly community. Shakespeare (2013) explained that while there are strengths to creating positive disability identity or “disability pride,” strict comparisons of disability to other minority identity groupings do not work: “Remove the social discrimination, and women and people of color and gay and lesbian people will be able to flourish and participate. But disabled people face both discrimination and intrinsic limitations” (p. 220). Scholars like Davis (2002) have argued that disability identity does not work because the power of disability is to disrupt categories and identities rather than to reify them. Disability, according to Davis, eludes clear definition; it “presents us with a malleable view of the human body and identity” (p. 273). Identity groupings narrow categories and disability, Davis believed, opening and crossing the boundaries of who *is* and who *is not*.

Identity construction has been an active conversation within autistic communities. A neurodiversity framework understands that brains operate in a variety of different ways and this diversity should be an expected variation of the human experience rather than pathologized (Broderick & Ne’eman, 2008; Singer, 1999). Although most often attributed to the autism community, neurodiversity can also be taken up across other disability communities, including Attention Deficit Disorder (ADD), dyslexia, Tourette Syndrome, and intellectual disabilities (Armstrong, 2011; Silberman, 2015).

Essential to this project is privileging autistic experiences and accounting for neurodiverse perspectives. Autobiographies have been hugely important in documenting the lives of disabled communities, especially autistics. In a field that presumes that autistics are male (which I explore in greater detail later in this chapter), autobiographies have been incredibly important places for autistic women's stories and subjectivities to be explored. Autistic scholar Melanie Yergeau (2018) argued that telling autistic stories is a radical act because autistic people have been de-storied and constructed as non-rhetorical; "in all things discursive, autism represents a decided lack" (p. 7). "Autie-biographies," i.e., autistic biographies (Yergeau, 2018), such as those by Temple Grandin (Grandin & Scariano, 1986) and Donna Williams (1992), have challenged damaging stereotypes of autistics as lacking an ability to understand their own and other's subjectivity. I explore this later in the chapter when I cover positivist research threads relating to Theory of Mind.

Julia Bascom's blog "Just Stimming" evolved into an edited book of autistic writings. Stimming refers to self-stimulatory behavior and can include rocking one's body, flapping one's hands, or humming (Bascom, 2012). Now the Executive Director of the Autistic Self-Advocacy Network, Bascom's interest in the book came from seeing her autistic community as resilient and needing to tell their own stories "in our own ways with our own voices" (p. 7). The anthology, *Loud Hands: Autistic People, Speaking*, is filled with powerful autistic women writers like Amy Sequenzia (2012), who described her use of her assistive technology to communicate: "[I have] loud hands. I must, since I use my hands to communicate. I type what I want to say" (p. 346). Sequenzia railed against those people who have historically dismissed her as "low functioning" and detailed the years of people talking *about,* but not *to,* her: "there is still a misconception that if you don't speak you can't understand, think or even hear" (p. 349). The anthology importantly

privileges many kinds of expression and knowledge construction. Amanda Forest Vivian (2012) chronicled in a series of pictures her stimming practices (Figure 4). Before taking the pictures, Vivian assumed that she "looked scary" (p. 337) but was eager to capture her movements and body because there were so few visual representations of autistic bodies stimming. The autistic body is a body that is often in motion, "always fluctuating, ticking, trembling" (Yergeau, 2018, p. 20). While the still image does not capture active motion, it is a snapshot of Vivian's (2012) autistic body finding a natural rhythm. She was eager to capture her body in a state of freedom.

Figure 4. *Amanda Forest Vivian (2012) Entitled "Run Forest Run: About Movement and Love" (p. 335) Self-portraits of Stimming*

Douglas Biklen (2005) co-authored a book with seven autistic adults (Attfield, Bissonnette, Blackman, Burke, Frugone, Mukhopadhyay, and Rubin) who use assistive technology to communicate. In *Autism: The Myth of Person Alone*, these authors dismissed the painful and damaging stereotypes of autistics as incapable, uneducable, and uncommunicative. All of these myths are built from an outsider perspective of autism that is deficit-oriented, and thus autistics constructed as abnormal. Autistics' knowledge and perspectives are ignored as experts establish and test theories around autistic behaviors (Biklen, 2005, p. 46).

Neurodiverse "autie-biographies" that document autistic cultural and communication practices like stimming and the use of assistive technology challenge ableist conceptions of "normal" behavior. Decentering normalcy is a DS tenet. DS scholars believe that conceptions of normalcy were historically created specifically in opposition to disability; "the state of 'normal' can only exist if it is disability free" (Baglieri et al., 2011, p. 2138). Scientific branches like statistics and evolutionary biology helped to construct the "normal" as White and able-bodied, or what Garland-Thomson (1997) termed "the normate" (p. 8). The concept of "norm" and words to describe it (normal, normalcy, normality, norm, average, abnormal) entered European languages in 1840 (Davis, 2013). The notion of "average" came from the field of statistics where in the 1830s, Adolphe Quetelet hypothesized the average man from mathematical notions of margins of error. The average man was both physically and morally good; therefore, those who fell outside of the bounds of average were constructed as inferior (Davis, 2013). The bell curve, the normal distribution curve, represents the "tyranny of the norm" (p. 3). Therefore, the extremities of the curve created deviance and disability. For every top 1%, there must be a bottom 1%. Put simply, "winners need losers" (Brantlinger, 2005).

When normal is seen as a neutral state, a disability-free reality, disabled knowledges go ignored or undervalued. Amy Sequenzia's (2012) insistence on being seen as capable as she uses assistive technology to communicate connects with a longstanding DS and DSE tenet of "presuming competence" (Biklen, 1990). Presuming competence means that there is an assumption that a disabled person is capable of thinking, learning, and understanding, even as the person may use an unconventional form of expression to display their understanding (Biklen, 1990, 2006; Goode, 1992; Kliewer, 1998). Biklen and Burke (2006) explained that it is important for an observer/teacher/parent/researcher "not to project an ableist interpretation on something another person does, but rather to presume there must be a rationale or sympathetic explanation for what someone does and then to try to discover it, always from the other person's own perspective" (p. 168). Just because a researcher or an educator does not understand a particular behavior does not mean the behavior is meaningless. Presuming competence is a touchstone in Disability Studies in Education (DSE) research.

Disability Studies in Education (DSE)

Disability Studies in Education (DSE), a branch of DS, specifically examines the ways in which schooling practices construct, understand, and educate children and disability. DSE challenges the "myth of the normal child" (Baglieri et al., 2011). Beginning in the 1800s in the United States, disabled students and students with mental illness were treated in medical facilities, asylums, and institutions. Interventions were based on a medical model of disability with a goal of a cure or repairing a child to a normal state: "to repair those minds that have been broken by the modern word" (Reiss, 2008, quoted in Price, 2015, p. 65). Violent and abusive techniques were commonly used in these facilities, including physical punishment, shock treatment, sterilization, and forceable drugging (Price, 2015).

As disability justice efforts intensified in the 1970s (specifically the Education of All Handicapped Children Act of 1975, reauthorized as IDEA in 1990), disabled students were more likely to be educated in Special Education settings rather than asylums; however, many scholars have argued that little had changed. Brantlinger (2004) noted that Special Education became another form of sorting and hierarchy: "If children do not match the statistical average, they are said to have risks, special needs, and learning disabilities" (p. 491). Special Education, steeped in medical practices of repair, became repositories for "abnormal" students. Despite the intention of the IDEA to educate students in the "least restrictive environments" (Colker, 2013; IDEA, 2014), many disabled students continue to attend specialized schools and specialized classrooms (Kauffmann & Hallahan, 1995; Sleeter, 1987; Stiker, 1999).

Baglieri et al. (2011) called for DSE scholars to embrace a more expansive understanding of inclusive practice. Rather than space- and place-specific, i.e., general education classroom vs. special education classroom, inclusion should be understood as a way to destabilize notions of normalcy that extend beyond disability categories and relate to all children. Inclusion would then extend beyond the abled/disabled binary: "inclusive education is about confronting all forms of discrimination as part of a concern to develop an inclusive society based on 'social justice, equity and democratic participation" (Barton, 1997, p. 233). I find Barton's and Baglieri et al.'s (2011) framing of inclusion to be particularly helpful for this project as it expansively understands inclusion beyond classroom walls and thus gives a theoretical lens to unpack embodied experiences of schooling and disability. At the end of this chapter, I return to notions of inclusion and the work of DSE scholars in framing schooling experiences for autistic youth.

Intersectional Framings of Disability, Difference, and Deviance

The underpinning of disability studies shares theoretical foundations with gender and race/ethnicity studies which view categories of gender, race, and disability as socially constructed and ever shifting. DS is strengthened when paired with other theoretical lenses that more specifically account for intersectional identities and power dynamics. In this section, I outline the ways in which DS intersects with feminist theory, critical race theory/DisCrit, and queer theory.

Feminist Disability Studies

DS is heavily influenced by feminist theory. Feminist theoretical framings of gender are particularly important for this project as I highlight the specific experiences of autistic women and complicated notions of gender. Feminist theory works to complicate the reduction of gender to biological sex; however, historically, feminist theory has under-recognized the role of disability in women's lives (Hall, 2011). Feminist issues, including discussions of reproductive justice/technologies, conceptions of the body and "ethics of care," and nurturance, have long excluded discussions of disability or disabled women (Garland-Thomson, 2011, p. 14).

Michelle Fine and Adrienne Asch's (1981) work was important in documenting the social location of the disabled woman from a feminist theoretical stance. They documented the economic, social, and psychological disadvantages of disabled women and theorized that the disabled woman was "roleless"; with no role models to emulate and no gendered expectations to either adhere to or to push against, "disability is a more severely handicapping condition for women than for men" (p. 233). They argued that "the disabled woman confronts the sexism experienced by most women, but is deprived even of the fragile pedestal of which non-disabled women are often placed" (p. 245). Disabled women are further marginalized by non-disabled

feminists who have linked disability with images of childlikeness, weakness, and dependence, and have "severed them from the sisterhood" in an effort to promote a more powerful and able image of femininity (p. 4).

Intersections of disability studies and feminist theory were further expanded by the work of Susan Wendell (1996) and Simi Linton (1998). Located in the overlapping categories of gender and disability, these disabled feminist scholars explored the location and construction of the disabled body. After experiencing chronic pain from myalgic encephalomyelitis, Wendell critiqued non-disabled feminists' celebration of the female body. Whereas non-disabled feminists locate the body as a source of pleasure or a space to reclaim from men's control or gaze, the disabled women's body is potentially a source of pain. Linton clearly defined the role of ableism in centering the able-bodied individual as the dominant perspective and called for radical visibility of disability.

> We have come out not with brown woolen lap robes over our withered legs or dark glasses over our pale eyes but in shorts and sandals, in overalls and business suits, dressed for play and work—straightforward, unmasked, and unapologetic. (p. 3)

Linton called for an "epistemology of inclusion" (p. 135) for disabled people into all aspects of society. Open and visible displays of disabled bodies were an important step towards open and public acknowledgment.

Hall (2011) acutely pointed out that *feminist disability studies* is not simply an addition of the two theoretical lenses: "understanding feminist disability studies as simply a combination of feminism and disability studies dulls its critical edge and lessens its potential to intervene in theoretical and social transformation" (p. 1). Rosemary Garland-Thomson's scholarship was essential to feminist disability studies and is credited with coining the term. In her review in the feminist journal *Signs*, Garland-Thompson (2005) offered that disability studies was particularly

important in informing three areas of feminist scholarship: identity, embodiment, and intersectionality (p. 1559). Other notable scholars in the field include Eva Feder Kittay (2003, 2009), who challenged traditional feminist critiques of care and independence/interdependence, as well as scholars who troubled conceptions of reproductive rights and the moral implications of eugenic reproductive bio-technologies (Adams, 2015; Kafer, 2013; Wong, 2002).

DisCrit and White Disability Studies

One of the most common critiques of the field of DS and disability activism is its lack of diverse perspectives. All too often, disability activism is led by, and reflects the interests of, White people (Moore, 2017). This trend continues into the academic work of DS where White academics dominate and the issue of race and racism is often ignored in research. Autistic scholars and activists like Lydia X. Z. Brown (2017) and Morenike Giwa Onaiwu (2017) have expressed frustration at the invisibility of autistics of color. Feeling as though they were often forced to place "race over here and disability over there" (Giwa Onaiwu, 2017, p. xii), their edited volume (the only one of its kind), *All the Weight of Our Dreams: On Living Racialized Autism* (2017), is a direct response to the ways in which both the field of DS and mainstream conversations around autism and autistic lives have ignored the unique experiences of autistics of color. Giwa Onaiwu wrote, "We—the autistics of color—are seldom acknowledged. Our faces, bodies, and voices are conspicuously absent from not only literature and media, but also from much of the discourse surrounding race and that of autism as well" (p. xi).

Lydia X. Z. Brown, a graduate from Northeastern University School of Law, is deeply committed to intersectional disability justice work. Identifying as an Asian non-binary, internationally adopted, and autistic, Brown is active in the Black Lives Matter movement and writes passionately about the ways the DS and disability justice field often ignores issues that

particularly impact disability communities of color: “disabled people of color are particularly vulnerable to state violence” (p. 423). Brown employed notions of intersectionality in their activism and scholarship. Intersectionality is a term attributed to the work of Black feminist scholar Kimberly Crenshaw (1989). As a legal scholar, Crenshaw was keenly aware of the way in which multiple oppressions overlap. A Black woman does not experience racism or sexism, but racism *and* sexism. Brown called for a more intersectional approach to activism and leadership in the autistic and disability activism community: “This is what intersectionality means: to practice social justice in ways that grapple with the complex impacts of multiple systems of structural oppression (or structural injustice)” (p. 424).

In an important and provocative essay, DS scholar Chris Bell (2006) proposed that the field of Disability Studies be changed to “White Disability Studies”:

> White Disability Studies recognizes its tendency to whitewash disability history, ontology and phenomenology. White Disability Studies, while not wholeheartedly excluding people of color from its critique, by and large focuses on the work of white individuals and is itself largely produced by a corps of White scholars and activists. (p. 275)

DS continues to ignore issues of race and racism. In a recent informal audit of the *Disability Studies Quarterly*, the most beloved DS publication, Karen Nakamura (2018) reported that in 2017, only four of the 47 published articles contained the words “race, racialization, black, or colonization.” Disabled women and girls of color are further ignored: “the ‘urban disabled girl of colour’ is virtually non-existent in professional or popular press” (Ferri & Connor, 2010, p. 106).

Disability critical race studies (DisCrit) emerged to address these fundamental flaws. DisCrit is a theoretical lens that explores the overlapping frameworks of disability studies (DS) and critical race theory (CRT) to “examine the interdependent constructions of race and disability in education and society in the United States (Annamma, Connor, & Ferri, 2016, p. 9).

CRT comes from critical legal theory and argues that racism is normal in US society (Delgado & Stefancic, 2001; Ladson-Billings & Tate, 1995). DisCrit interrogates the unique ways that racism and ableism work in tandem to reinforce White supremacy and status quo power structures that position the White, able-bodied, Christian, straight, cisgender male as normal (Annamma et al., 2016). Latino and Black children make up a disproportionate number of students in the special education system. Erevelles and Minear (2010) argued that this systematic segregation of brown bodies to segregated settings is a reinscription of Jim Crow Era laws, which worked to perpetuate oppression and eugenics agendas. If DisCrit urges for an examination of the interlocking dynamic of gender, race, and ability and for more complicated understandings of these categories, queer theory works to undo the very notion of categorization.

Queer Theory, Crip Theory, and Neuroqueer

Queer theory questions binary thinking: homo/hetero, male/female, deviant/holy (Butler, 1993; Jogese, 1996) and allows for messy categories and fuzzy edges of identity. The word "queer" has origins as a pejorative word for homosexual but has been reclaimed as an expansive identity marker for the Lesbian, Gay, Bisexual, Transgender, Intersex, and Asexual (LGBTIA) community. To queer is to disrupt, to make unstable:

> Queer must insist on disturbing, on queering, social organization as such—on disturbing, therefore, and on queering *ourselves* and our investment in such organization. For queerness can never define an identity; it can only ever disturb one. (Edelman, 2004, p. 17)

Queer/gender theory makes the distinction between sex and gender. Chromosomal sex is biological differences based on chromosomal factors. Gender is the social construction/ production of male and female identities (Butler, 1993; Sedgwick, 1990).

In *Epistemology of the Closet*, Eve Sedgwick (1990) argued that the homosexual/ heterosexual binary is elemental to all of Western epistemology. The heterosexual only exists in relation to the homosexual. Normal (heterosexual) is defined by what is abnormal (homosexual). Both DS and Queer scholars work to decenter conceptions of natural or normal. Queer theory positions itself as slightly askew of the mainstream gay rights agenda. Cohen (1997) and other queer theorists, particularly scholars of color, were critical of the mainstream gay rights agenda, specifically their Civil Rights Era strategy, which focused on access to gay marriage and military service "where assimilation into, and the replication of dominant institutions are the goals" (p. 437). Mainstream gay agendas most often benefited White, middle-class lesbians and gays and ignored the realities of transgender and queer people of color (ex: health care, police violence). Gay and lesbian rights agendas that worked towards assimilation simply expanded the edges of normalcy and did little to challenge underlying institutions of homophobia (Sandahl, 2003).

DS scholar Robert McRuer (2006) pulled heavily from queer theory in his work *Crip Theory*. Influenced by feminist/gender scholar Adrienne Rich (1980), McRuer saw crip theory as questioning the inherent "compulsory able-bodiness" of society. Rich argued that society was organized with the assumption of heterosexuality, heterosexuality was created as a norm, and thus homosexuality was constructed as the deviant. Rich called this "compulsory heterosexuality." McRuer argued that "compulsory able-bodiness" is even more engrained into our Western epistemology. "Able-bodiedness, even more than heterosexuality, still largely masquerades as a nonidentity, as the natural order of things" (p. 1). Kafer (2013) argued that in naming "compulsory ablebodiness," there is often a silencing or an ignoring of "compulsory able-mindedness." Her work encourages DS theory to be inclusive across disability categories and to avoid the pitfalls of the foundations of DS scholarship, which often privileges physical

disabilities rather than embraces a more expansive understanding of the disability spectrum (Egner, 2019).

McRuer (2006) is a bit elusive in defining the term *crip* as it is, by nature, nebulous. I find Sandahl's (2003) working definition helpful:

> The term crip has expanded to include not only those with physical impairments but those with sensory or mental impairments as well. Though I have never heard of a nondisabled person seriously claim to *be* crip (as heterosexuals have claimed to be queer), I would not be surprised by this practice. The fluidity of both terms makes it likely that their boundaries will dissolve. (p. 27)

Like the term *queer*, *crip* has been reclaimed from the pejorative word "cripple." A crip identity is a more expansive definition of disability that is fluid and ever-changing.

In explicating "crip" theory, Kafer (2013) also offered the notion of "crip time." Crip time can be understood as a form of a "queer temporality" (Halberstam, 2005; Munoz, 2009), a queering of traditional notions of linear time and futurality (Edelman, 2004). Crip time is a flexible standard of punctuality where disabled bodies often need more time to navigate spaces as well as the time that is often taken for granted in the day-to-day lives of disabled people. Ellen Samuels (2017) described the slipperiness of crip time, not only as a "form of liberation" but also as a "site of loss and alienation" (p. 1).

> …we who occupy the bodies of crip time know that we are never linear, and we rage silently—or not so silently—at the calm straightforwardness of those who live in the sheltered space of normative time.[…] For crip time is broken time. It requires us to break in our bodies and minds to new rhythms, new patterns of thinking and feeling and moving through the world. It forces us to take breaks, even when we don't want to, even when we want to keep going, to move ahead. It insists that we listen to our bodyminds so closely, so attentively, in a culture that tells us to divide the two and push the body away from us while also pushing it beyond its limits. Crip time means listening to the broken languages of our bodies, translating them, honoring their words. (Samuels, 2017, p. 1)

Kafer (2013) used the example of Access-A-Ride, the free service for disabled people who do not/cannot use public transit. Often passengers will wait in limbo for hours for their rides to

arrive (p. 26). In this way, having a disability means that one's time is less valued than able-bodied individuals, while simultaneously disabled bodies are rushed and pressured to conform to standard notions of time. Kafer urged a radical departure from ableist notions of linear time: "Rather than bend disabled bodies and minds to meet the clock, crip time bends the clock to meet disabled bodies and minds" (p. 27).

Evolving from crip temporalities and shifting identities is the concept of "neuroqueer." Autistic DS scholar Melanie Yergeau (2018) was one of the first to take the term into academic circles. The term originated from autistic blog culture, including Ibby Grace, Athena Lynn Michaels-Dillon, and Nick Walker (Yergeau, 2018, p. 27). As a concept, it is slippery to pin down, difficult to define: "Neuroqueer identities are those in which subjects perform the perversity of their neurotypes" (Yergeau, 2018, p. 27). Autism queers social orders, social organizations, and typical behavioral expectations. Like crip, neuroqueer is a purposely porous category that can include many neurodiverse brains, including individuals who question the realities of categories of gender, race, and ethnicity (Yergeau, 2018).

Having thus mapped the theoretical landscape of my project, in the next section, I outline the research framings of autism. A majority of autism research does not examine schooling or educational contexts and instead represents a heavy medicalized and positivist notion of autism as an epidemic problem, an issue to be understood and cured. It is essential to cover this research thoroughly, however, as these positivist framings of autism have become common sense and seep into school systems, school staff perspectives, and intervention strategies.

A personal anecdote: Recently, I was having lunch with a friend of mine who is a speech therapist. She has been in the field for over 15 years working in schools and I consider her to be respectful and supportive of neurodiverse perspectives. When I told her about my project, she

simply stated, “Well, girls with autism are really rare because of their genes. It’s a genetic and hormonal thing.” Then after a minute, she paused and said, “I guess I just don’t think about autistic girls specifically that often because I have so few on my caseload.” Schooling does not often intersect with discussions of autism, and autism research does not often engage in conversations around gender. I am attempting to bridge this gap.

Positivist Approaches to Autism Research

The majority of the research done about autistic women, and autistics in general, comes from a positivist medical perspective. I use the term *positivist research* because these kinds of studies approach research from an epistemology that believes that, through science, knowledge can be gained (Comte, 1883; Hughes, 2010). Positivist methodological approaches use standardized measurements to establish quantifiable and objective information that is observable (Coolican, 2013). The researcher is not a participant but a detached observer (Hudson & Ozanne, 1988). Researchers in the positivist branch of autism research use standardized measurement tools, including IQ test scores, normed autism assessments (i.e., ADOS [Gotham et al., 2006] and CARS [Schopler et al., 2010]), genetic information, and behavioral checklists that count observable autistic behaviors such as “stimming” or verbal or physical outbursts.

I begin the next section with an exploration of the work of the four biggest researchers in the autism field: Leo Kanner (1943), Hans Asperger (1944), Ivar Lovaas (1987), and, most recently, Simon Baron-Cohen (1995). I outline their work historically to trace the ways that particular assertions about autistics and autism research have been passed through generations of research, the reverberations of which are still felt in the field, including the domain of school interventions and educational supports for autistic students. In the section following immediately, I briefly cover more recent autism research that specifically examines gender and

autism and posits that there is a genetic reason for the gender gap in diagnosis. I subsequently offer alternative framings of gender and autism that suggest that autism looks differently at girls and women; therefore, women and girls are going undiagnosed.

As I explore the articles in this section, I use the language they employ; therefore, vocabulary like "high-functioning," "cognitive impairment," "normal," "deficit," and "vulnerable to ASD" is used to ground this particular medicalized epistemology and to approach their research from their particular construction of autism as "a problem" to be fixed. Studies of this strand come from the fields of psychology, psychiatry, and epidemiology. The rest of this project works to push against this kind of dehumanizing rhetoric which positions the autistic person as a depersonalized body on which to "do research."

Kanner's (1943) "Autistic Disturbances" and Asperger's (1944) "Male Intelligence"

In order to contextualize current autism research, a historical perspective is essential. Key assumptions around autistic deficits as well as the assumption of autism as a gendered and racialized category emerged from Kanner's (1943) and Asperger's (1944) original research. Kanner's original studies were comprised of 11 children, eight of whom were male and all were White. Kanner was fascinated by what he called the "autistic disturbance" in these students. He described these clustered characteristics as avoidance of social interaction, repetitive behaviors, overall good physical health, expressive language challenges and/or echolalia, a fascination with objects, and an inflexibility or a rigidity towards change (Kanner, 1943; Silberman, 2015, p. 274).

These traits could be found in his first case study, Donald, a 5-year-old boy who Kanner (1943) described as having a strong memory but was "happiest when left alone, almost never cried to go to his mother, did not seem to notice his father's homecomings and was indifferent to

visiting relatives" (p. 218). Kanner detailed the ways in which Donald did not seek out nor accept physical contact or affection, and instead "lives within himself." Although Donald had frequent and violent temper tantrums, Kanner believed that the boy was incapable of understanding consequences or punishment from his parents. Lacking the cognitive ability for "abstraction of the mind" (p. 218), Donald preferred the world of objects, specifically spinning tops and repetitive play.

While the males in the study like Donald, Fredrick, and Richard M. were described as "self-absorbed" but "quietly intelligent" (p. 225), case participant Barbara was described as "very timid, fearful of various and changing things […] mostly passive […] just kept quiet" (pp. 228-229). From its inception, the autism category was being defined in gendered ways. Both boys and girls were categorized as struggling with social interaction, but the boys were more likely to be assumed to have an inner intelligence while the girls were described as quiet, passive, and fearful. This descriptive trend continued in Kanner's portrayal of Virginia, a 10-year-old girl who Kanner described as "neat and tidy [….] but does not talk" (p. 231). Unlike Donald who was quick to tantrum, Virginia was "not resistant to authority or caused any special trouble" (p. 231). Virginia was celebrated because of her adherence to gendered understandings of acceptability. For girls, this means an attractive appearance and overall passivity.

The work of Asperger (1944) in Vienna, Austria, also documented a gender differential. In describing "autistic intelligences," Asperger described three case studies, which represented a larger gestalt of the autism spectrum (Draaisma, 2009). Fritz, who excelled in mathematics, was prone to violent outbursts and clumsy, spoke eloquently in a high-pitched voice, and used extensive vocabulary. Harro, too, had a propensity for mathematics, used an adult vocabulary, and had violent outbursts. Ernest, also with a talent for sums, lacked social skills, craved

routines, and did not show interest in others. In all of Asperger's 200 cases, there were no girls (Asperger, 1944; Draaisma, 2009). He noted the lack of girls in his study:

> While we have never met a girl with the fully-fledged picture of autism, we have, however, seen several mothers of autistic children whose behavior had decidedly autistic features. It is difficult to explain this observation. It may be only chance that there are not autistic girls among our cases, or it could be that autistic traits in the female become evident only after puberty. We just do not know. (quoted in Silberman, 2015)

Later in his research, Asperger seemed to close the door on the possibility of women autistics and described autism as "an extreme variant of male intelligence" (quoted in Silberman, 2015).

Some key assumptions about autistics emerged from Kanner's (1943) and Asperger's (1944) original studies. They are mainly fourfold:

1. Autistics are asocial and walled off from the world.
2. Autistics operate very differently from normal human behavior.
3. Autism is an inborn/organic trait that occurs in infancy.
4. Autism is a male category.

These assumptions continue to underline the majority of the mainstream autism research today (Bascom, 2012; Broderick, 2011; Murray, 2012; Silberman, 2015; Yergeau, 2018).

Lovaas' (1987) Applied Behavior Analysis (ABA)

So what is to be done with these children who are walled off, separate, and hard to reach? Psychologist Ivar Lovaas (1987) was one of the first to aim explicitly to create an intervention for autistic children that would make them indistinguishable from their typical peers. This intervention went on to be named Applied Behavior Analysis (ABA) and is the most widely used intervention for autistics to date. Following the work of B. F. Skinner (1953), Lovaas (1987) understood autism to be a disorder of motivation and used punishments and rewards to build

skills. Simply put, when behavior is rewarded, it continues. When it is punished or ignored, it stops.

Lovaas (1987) described his case study students in similar ways to Kanner (1943): "Autistic children show minimal emotional attachment, absent or abnormal speech, retarded IQ, ritualistic behaviors, aggression and self-injury" (p. 3). Lovaas' research hinged on the notion that although "normal children learn from their everyday environments…autistic children conversely do not learn from similar environments" (pp. 3-4) and thus require highly controlled one-on-one, adult-directed intervention to learn. His early pilot study work began in the 1960s out of the University of California with four autistic children, three boys and one girl. *Life Magazine* (Moser & Grant, 1965) did a photo essay entitled "Screams, Slaps, and Love: A Surprising, Shocking Treatment Helps Fargone Mental Cripples," which documented this early work. It photographed a psychologist screaming into the face of a young boy. In perhaps the most disturbing photo, a young girl is shown entering the

> shock room where the floor is laced with metallic strips. Two electrodes are placed on her back and her shoes are removed. When she resumes her habit of staring at her hand, Lovaas sent a mild jolt of current through the floor into her bare feet. (Moser & Grant, 1965, p. 94)

Physical affection and food rewards were used as rewards or breaks from the 8-hour intervention days.

Lovaas (1987) is best known for his work in the 1980s when he designed a control and intervention study for autistic children. The intensive group received 40 hours a week of one-to-one behavioral intervention and the control group received 10 hours a week of one-to-one behavioral intervention. All children were under 46 months of age and had a chronological age of at least 11 months (p. 4). Lovaas reported that the intensive treatment group made significantly more gains and that nine out of 19 children (in the intensive group) achieved

average IQ scores, thus deeming them "recovered" from autism (p. 8). Lovaas' ultimate goal was an autistic cure.

Before becoming famous for his work with autistic children, Lovaas used some of his techniques from his pilot study (Moser & Grant, 1965) to correct gender non-conforming children. Lovaas, in collaboration with fellow graduate student George Rekers, began studying the foundations of behavioral interventions in a single-subject study with a 4-year-old boy (1974). Young "Kraig" displayed "cross gender identification" and sought out women's clothing, displayed feminine mannerisms, and pretended to put on make-up. Rekers and Lovvas set out to correct Kraig's gender divergence. Treatment was essential because without it, Kraig would most likely lead a "miserable social life" (p. 174) that would include being an adult transexual, homosexual, or another form of "sexual deviance" (p. 175). Rekers and Lovaas (1974) explained that it was easier to transform Kraig than it was to change the social stigma and attitudes towards cross-gender identification.

Rekers and Lovaas (1974) were explicit about what they considered appropriate feminine and masculine play and served as a kind of "how-to" guide to gender stereotypes. Feminine toys included make-up, dolls, and hairbrushes; masculine toys included football helmets, dart guns, and plastic handcuffs. Feminine toys induced nurturance, whereas masculine toys were described as eliciting aggressive play (p. 176). Kraig was observed playing with these toys in a lab setting and his play was coded as masculine or feminine. His scores were then compared to "normal" same-aged children (p. 177). When Kraig played with masculine toys, he was praised or received a token. When he played with feminine toys, he was ignored and/or tokens were removed. Tokens were then saved and traded in for candy. Tokens, candy rewards, planned ignoring, and isolation are all still used in ABA interventions, including in school settings. The goal for

Kraig's intervention was to "extinguish" feminine behavior (p. 179), and to reach that goal, deterrents were used, including spankings and social isolation (p. 180). After a 3-year follow-up, Lovaas and Rekers (1974) declared that Kraig's treatment was a success and that his "sex type behaviors have become normalized" (p. 181).

Lovaas and Rekers built their careers on this study and on successfully "curing" the boy's sex role deviance. Lovaas used the research from this 1974 study to focus specifically on autism and went on to create ABA, the most widely accepted autism intervention in the United States. George Rekers continued his career as a psychologist by focusing on "curing" homosexuality. He cofounded the Family Research Council (FRC), the most powerful anti-gay religious organization in the United States that has been at the forefront of fighting the legalization of gay marriage and attempting to block gay parent adoptions (Emery & Schmidt, 2012). Rekers popularized gay conversion therapy movements in the US, which included shock treatment, verbal abuse (Hamilton & Henry, 2009), and what survivor Garrard Conley (2016) as a form of mental torture.

ABA and gay conversion therapy take a curative approach that measures their success rates on the erasure of deviance. True recovery is measured by the erasure of a deviant, gender non-conforming, autistic identity: "autism treatment enterprises, many of which share origin stories with gay conversion therapies, enact a rehabilitative response as a means of de-queering the autist" (Yergeau, 2018, p. 27). Queer theorist Judith Butler described this erasure and its consequences on the deviant body: "Life itself requires the norm, while living outside the norm involves placing oneself at the risk of death—sometimes actual death, but more frequently the social death of delegitimation and non-recognition" (quoted in Salih & Butler, 2004, p. 11). Gay conversion therapy has been banned in 35 states (Conley, 2016), whereas ABA intervention

treatments continue to be the most widely used autism "treatment" approaches in schools and in after-school or in-home support services (Silberman, 2015). DSE scholar Alicia Broderick (2011) explained that ABA is positioned as a neutral, scientifically supported intervention. With the goal of recovery, ABA has created a rhetoric of autism as "enemy" (p. 17). Autism is therefore constructed as a "disease, epidemic, abductor" (p. 17) to a mythologically "normal" child that is disease-free (Broderick & Ne'eman, 2008). Framing autistics as having a fundamental "lack" (Yergeau, 2018, p. 7) continues as a theme in the work of the next researcher, Simon Baron-Cohen (1995, 2003).

Baron-Cohen's (1995) Theory of Mind and Extreme Male Brain

Building from Kanner's (1940) notion of autistics as "walled off," a strand of autism research claims that autistics lack a "Theory of Mind" (Premack & Woodruff, 1978). Baron-Cohen is the most known researcher in the field. Theory of Mind is a concept that comes from the field of psychology. Psychologist Jean Piaget (1923) described young children as "egocentric" and incapable of understanding other people's perspectives. Researchers Wimmer and Perner (1983) reported that Theory of Mind, the skill to "represent a person's beliefs" (p. 104), is a skill that first emerges in children ages 4-6 and then later solidifies with children's development.

Baron-Cohen (1995) argued that autistic people lack a theory of mind and it is in fact this inability to understand the perspectives of other people that is at the core root of autism. He named this inability "mindblindness" or "the condition of failing to recognize and understand mental states" (p. 145). Baron-Cohen began his chapter on autism and mindblindness by quoting developmental psychologist and Theory of Mind researcher, Henry Wellman (1985). Wellman described a "hypothetical being" who "knows nothing of internal mental states of themselves or

others" and nothing of the "social world" (p. 169). He described these mythical beings as "impoverished creatures" (p. 169). Baron-Cohen explained, "There are real children—not hypothetical beings—who suffer from mindblindness as a result of damage either to shared attention mechanisms or theory of mind mechanism system. These children have autism" (p. 60). Theory of Mind research, specifically the work of Baron-Cohen (1995), constructs autistics as non-human. Autistics are not capable of inter-emotional reflection. Other people's thoughts and feelings are alien to autistics: "Autistics are not only antisocial, defying the bounds of multiple social fabrics, but we are the ultimate asocial beings, forwarding self over others, humanizing objects and objectifying humans, rigid in our gaze and our gait and our affect" (Yergeau, 2018, p. 27). The autistic is located completely outside of the scope of normal human variation.

The next phase of Baron-Cohen's work examined the role of intelligence and sex. Building from this Theory of Mind research, Baron-Cohen revisited some of Asperger's (1944) claims of autistic intelligence and the connection to biological sex. He argued that the male brain is better equipped to excel in systemizing and the female brain excels at empathizing. Levels of testosterone determine female and male brains. Autism serves as the perfect test case for Baron-Cohen's (2003) reductionist theories of gender and neurology. Echoing the descriptions of Kanner (1943) and Asperger (1944), Baron-Cohen (2003) described autistics as "loners" and those who are incapable of empathy. Empathy, he noted, was a skill in which females excel, compared to males. Females scored the best, then males, then autistics. Baron-Cohen believed that autism rates in males are 10 times higher than in females (2003) and he nearly erased the possibility of autistic women.

Baron-Cohen's (2003) research is not fringe. It is mainstream and well accepted by the research community. What his work does, DS scholar Yergeau (2018) argued, is positions

autistics as unintentional, i.e., "autistics lack intentionality because their supposedly excessive testosterone wields intentions for them" (p. 71). Threads of "extreme male brain" and "Theory of Mind" are found throughout current autism research. Many of the studies that are mentioned in the following pages list Baron-Cohen as the ninth or tenth author on large-scale autism studies. Interventions for autistic children, specifically ABA, accept these theories and locate the autistic as separate, abnormal, and in need of a cure.

Recent Research on Gender and Autism

Research focused on gender and autism is scarce and accounts for a small fraction of autism research. Of this small group, nearly all of these studies examine the genetic causation of the ratio diagnostic differences between men and women (4:1). I call these studies genetic and biological framing of autism and gender. A very small second group of studies, alternative framings of gender and autism, looks at gender and autism very differently. These studies propose that autistic women present differently than autistic men and that women are masking signs of autism.

"Genetics": Biological Framings of Gender and Autism

The work of Kanner (1943), Asperger (1944), Lovaas (1987), and Baron-Cohen (1995, 2003) created the backbone for the majority of research on autism. Current research on autism is overwhelmingly positivist and continues to focus primarily on causation. These kinds of studies operate with the same assumptions of autistics as walled off, asocial, and remarkably "different" (Biklen, 2005; Murray, 2012; Yergeau, 2018). Autism is accepted without much question as a majority male disability. Sarah Hendrickx (2015) explained, "Research that investigates and differentiates the male and female profile, presentation and experience of autism is fairly scarce, thereby perpetuating the myth that autism is significantly male-dominated condition or

alternatively that gender is simply not a consideration" (p. 22). It was not until the most recent *DSM-V* (APA, 2013) that sex or gender was mentioned beyond sex ratio statistics: "In clinic samples females tend to be more likely to show accompanying intellectual disability, which suggests that girls without accompanying intellectual disability or language delays may go unrecognized, perhaps because of subtler manifestation of social and communication difficulties" (p. 57). The *DSM*'s acknowledgment that indeed autism may be different for women puts an onus on researchers to examine these differences.

Research that does include or focus on autistic women approaches the research from a causation framework. These studies examine the biological theories around sex ratio differences and look for biological reasons why males with autism outnumber women with autism 4:1 (Maenner et al., 2020). Within this field of research are two major biologically based theories around the differences in ASD diagnosis. The first group of research posits that females are less "vulnerable" (Lai et al., 2011) to ASD due to specific biological mechanisms that also reduce the rate that women will develop other developmental disorders. The second group of researchers wants to measure the specific levels of autistic behaviors in girls and boys, believing that an inborn difference in sex inherently accounted for higher ASD rates in boys. I think these are important to explore as these have become accepted as common understandings of sex and gender disparities in autism diagnosis while, in reality, these research studies are merely theories. Below, I outline some of the most referenced articles published in well respected and peer-reviewed journals that represent this particular strand of genetic and biological autism research.

The first group of research examines the role of chromosomes and ASD. This body of research accounts for a large majority of autism research. The accepted theory within this research cluster believes that autism rates in males are much higher than in women due to

chromosomal differences. Cisgender females have XX chromosomes and cisgender males have XY chromosomes; therefore, these researchers have argued that genetic and chromosomal factors explain the fact that males are diagnosed with autism at four times the rate as women. This research has grown out of previous research that examined the chromosomal connections of other disabilities such as Down syndrome, which is associated with three copies of chromosome 21 (Lejeune et al., 1959). Mariner et al.'s (1986) work suggested chromosomal imbalances in children with cognitive disabilities, and as technology and time advanced, researchers specifically examined the chromosomal links in autism (International Molecular Genetic Study of Autism Consortium, 2001), but were only able to suggest early indicators of connections to ASD. In the 2000s, researchers pointed to new chromosomes for causation including chromosome 15 (Bass et al., 2000; Rosenfeld et al., 2013); chromosome 16 (Fernandez et al., 2010; Kumar et al., 2008; Weiss et al., 2008); chromosome 17 (Oliver et al., 2011); chromosome 22 (Schneider et al., 2014); and chromosome 3 (Glassford et al., 2016). Ultimately, these studies suggested that there is no one autism gene; instead, multiple areas of the brain are affected by ASD (Bergbaum & Mackie Ogilvie, 2016). Biological theories that males are more susceptible to ASD due to chromosomal factors are at this point unsubstantiated by current research (Halladay et al., 2015). If anything, this research further supports the notion that so much more is unknown about autism and gender.

The specific findings in each of these studies is beyond the scope of the present research do little to address the core questions that I ask here. However, these kinds of studies do represent current trends in autism research and the kinds of research that are being funded. Each of these studies is initiated by a team of researchers from higher education settings. The goal of this research is to identify an "autism gene" or to perhaps move forward with pinpointing the

exact genetic precursors to ASD. Once these genetic abnormalities are identified, they can be screened for and potentially eliminated. Autism is placed in the same category as any other unwanted and harmful condition. It is described as a "severe deficit" and "dysmorphism" (Bergbaum & Mackie Ogilvie, 2016, p. 620) that affects "normal brain development" (p. 626).

The second group of researchers sought to measure the specific levels of autistic behaviors in girls and boys and argued that inherent inborn differences between males and females resulted in higher ASD rates for boys. Psychologist Lorna Wing (1981) was one of the first researchers to ask questions explicitly around sex ratios in autism diagnosis. Her research (1981) suggested that gaps in the sex ratios of autistic girls and boys were smaller in children who had IQs higher than 50, as compared to children with IQs less than 50. She posed that girls' "natural skills in language" (p. 136) inhibited an ASD diagnosis, and therefore male children were more "vulnerable" (p. 136) to developing ASD.

Wing's (1981) focus on language and her belief in inherent biological skill differences between girls and boys persist in many studies of sex and autism. A cluster of research studies specifically measured the differences between "repetitive and stereotyped autistic behaviors" and verbal communication skills (Mandy et al., 2012, p. 1305). This branch of research is inconclusive and has produced a wide range of varying results. While some studies reported that autistic girls had fewer repetitive behaviors and higher language skills (Hartley & Sikora, 2009; Lord et al., 1982), other research has suggested opposite results—that girls displayed higher rates of repetitive behaviors and low language output (Carter et al., 2007; McLennan et al., 1993). Still, a third body of research has suggested that there is no difference in language and behavior based on sex (Holtmann et al., 2007; Volkmar et al., 1993). Part of the inconsistent results is a byproduct of sample size. Mandy et al. (2012) explained that these studies (Holtmann et al.,

2007; Kopp & Gillberg, 2011; Pilowsky et al., 1998) suffered from inconsistent population sizes between female and male participants due to the "rarity of females with ASD" (p. 1305). This meant that their sample sizes for autistic women were so small, as compared to the male participants, that their results were inconclusive (Mandy et al., 2012). This is a recursive problem. Because there are fewer rates of autistic women and girls, they are less represented in research sample sizes; therefore, the validity and richness of research findings are compromised.

Mandy et al.'s (2012) study produced perhaps the most interesting results out of this field of research. They reported "subtle" differences between male and female autistics (p. 1310) after collecting a variety of different data sources, including standard data (Autism Diagnostic Observation Schedule scores [Gotham et al., 2006] and IQ scores), with additional data coming from parent and teacher interviews. It is crucial to note that their data collection *did not* include interviews with autistic girls themselves.

Mandy et al. (2012) noted that autistic boys were more likely to externalize their emotions (i.e., outbursts) whereas girls were more likely to internalize their emotions, resulting in higher rates of anxiety and eating disorders (pp. 1311-1313). Based on teacher and parent reports, boys overall displayed an increased rate of "hyperactivity" and challenges in "social relationships," implying that perhaps boys have greater difficulty "adapting to the school environment" as compared to girls (p. 1311). However, as Mandy et al. (2012) keenly pointed out: "An alternative, and not mutually exclusive, explanation is that more of the difficulties experienced at school by females go unnoted by their teachers" (p. 1311). Considering teachers are often the source of a referral for an ASD diagnosis (Posserud et al., 2006), teachers' inability to recognize gender-specific ASD symptoms is a barrier for support services for girls.

The research of Mandy et al. (2012) suggested that because clinicians rely on external behaviors like meltdowns and repetitive behaviors, girls are being underdiagnosed. This was mentioned as a potential design flaw to their own study:

> In the current study, to ensure we were investigating difficulties of relevance to autism, participants had to have an ASD diagnosis to meet inclusion criteria. Yet the diagnostic criteria we used are arguably derived from male cases. Accordingly, it is possible that we excluded individuals with characteristic female phenotype, thus *underestimating* true sex differences. (p. 1312)

Furthermore, Mandy et al. (2012) suggested that women with ASD are able to compensate over time; therefore, studies that include young girls (under 7) as compared to studies that focus on adult women will vary greatly based on these women's ability to "adopt compensatory social communication strategies over time" (p. 1305).

Mandy et al. (2012) made the distinction between genotype and phenotype, terms coming from the biological/epidemiology fields. A genotype (genes) is the heritable genetics of an individual, whereas a phenotype is the interaction between genetic and environmental and life experience which determine someone's physical and personality characteristics (Grove et al., 2016). Mandy et al.'s (2012) study represents a newer theory regarding autistic women, that there is a specifically different phenotype of autism for women. Plainly put, then, autistic women are different than autistic men and the current diagnostic criteria for autism may not sufficiently represent or include autistic women traits. The challenge is that currently, the kind of research that reports this is heavily positivist and looks to genetic information, IQ tests, and autism rating scales to document these differences between male and female autistics. Qualitative research that forefronts autistic women's experiences from a phenomenological perspective (Bogdan & Biklen, 2007) can provide deep, rich, and complicated contextualization of the real lived

consequences of these diagnostic gaps and gender differences. This is the gap that I hope my research can address.

"Camouflage": Alternative Framings of Autism and Gender

Diagnosticians, families, and teachers expect autistic girls to look the same as autistic boys and do not account for the ways in which autism is expressed differently in girls; therefore, there is a male bias towards diagnosis (Dean et al., 2014; Dean et al., 2017). One way to unpack this discrepancy is to understand that girls are better at "camouflaging" their ASD symptoms (Dean et al., 2017; Dworzynski et al., 2012; Hiller et al., 2016). Girls with ASD may be better at mimicking the play behaviors of their allistic (non-autistic) peers, such as imaginative play or even voice tones and mannerisms (Attwood & Grandlin, 2006; Kopp & Gillberg, 1992). Cook et al. (2018), researchers from the UK, called this "masking their autism" (p. 309). They shared an excerpt from an interview with Leah, a 12-year-old autistic girl who attends an inclusive school setting.

> I was like 'oh should I change into someone else? because no one actually seems to be in the group so I, I thought if I changed to be like my other friend, they'll listen to me, and they all did, so I was like, I'll keep it that way…. I'm changing because no one's actually listening to me and I always feel left out. (p. 310)

This kind of masking can lead to late diagnosis. Leah was diagnosed with ASD at the age of 10 (Cook et al., 2018).

Autistic girls may have a harder time joining traditional girl play and thus may struggle in school social groupings. Dean et al. (2017) examined the playground dynamics of children at school and suggested that girls' play is more fluid than boys; girls move in and out of smaller groups of play, whereas boys were more likely to engage in structured physical play with clearer rules. Children often play in sex-segregated groups (Dean et al., 2014); therefore, autistic girls were often observed on the periphery of these groups in school, but were not actively engaged in

the play (Hall, 2010; Maccoby, 2002). Dean et al. (2017) explained that autistic girls observed but did not actively join social play: “The fluidity of female social groups created an ideal backdrop to conceal the girls with ASD who were often hovering close by” (p. 685). School support staff therefore missed the ways that autistic girls were being excluded in schools and their behavior was interpreted as “shy, good or teacher’s pet” (Bargiela et al., 2016). In an essay aimed at parents of autistic girls, Katie Levin (2017) detailed some of the ways that she as an autistic girl did not fit in school: “Just because I may be well-behaved, quiet, and getting good grades at school doesn’t mean that school is going well” (p. 50). The theme of hiding in plain sight is a common one for autistic women.

If autistic boys are more likely to be bullied by allistic peers, autistic girls are more likely to be ignored by their school-aged peers (Asher et al., 2001). Additionally, if a girl receives a diagnosis of autism, autism support services, specifically social skills groups that are designed to support social play, are dominated by autistic boys due to the current discrepancy in diagnostic rates (four boys to every one girl) (Maenner et al., 2020). If “girl” and “boy” play is indeed different, then autistic girls are missing important play opportunities that may be attached to gender-specific groupings that impact their school relationships (Cridland et al., 2014).

Autistic women reported that they often did not fit typical notions of femininity, which can complicate peer dynamics. Sarah Hendrickx (2015) called this the “tomboy” profile. Hendrickx explained that autistic women often communicate in very straightforward ways that are not traditionally viewed as “feminine or girly” (p. 152). Some preliminary research has suggested that there are higher rates of transgender, gender-fluid, androgynous, and/or non-binary identities within the autistic community (Van Der Miesen et al., 2018). This newly emerging research is also echoed within some autistic communities. Hendrickx (2015) noted that

of the 50 women she interviewed, only half of them identified as heterosexual; instead, many participants took a "blank canvas approach to sexuality" (p. 160) and did not feel the need to define their sexual preferences or identities. Exploring the gender identities of autistic women and how those identity formations are influenced by schooling experiences was a focus of my project.

Girls and women who do receive an autism diagnosis are often diagnosed much later in life (Begeer et al., 2013; Giarelli et al., 2010). To receive a diagnosis, girls have to display more cognitive impairments and more obvious behavioral problems than their male peers who receive a diagnosis (Dworzynski et al., 2012). Bargiela et al. (2016) interviewed 14 late-diagnosed autistic women. An important theme was feeling as though they needed to "wear a mask." A huge majority, 12 out of 14, of the women received other diagnoses including depression, anxiety, eating disorders, and multiple personality disorder. One participant shared "four or five years of depression and anxiety treatment…years of talking therapy…and not once did anyone suggest I had anything other than depression" (p. 3286). The daughter of another participant, Tina, only received an autism diagnosis at the age of 12. Tina described her daughter's pre-diagnosis school life as "hell" (Cridland et al., 2014, p. 1265). Without a diagnosis to help guide the family on how to support their child, teachers became frustrated with her daughter's challenges and, without a framework to understand her, they labeled her "a bad kid" (p. 1265).

Anecdotally, it is common to hear women share that they only received a diagnosis after their own children were diagnosed. Giwa Onaiwu (2015) received a diagnosis after two of her children were diagnosed with autism:

> I only wished I had this awareness when I was much younger. It would have helped me understand how to better operate, learn, handle challenges and socialize. I could have avoided costly mistakes, made different choices and sought strategies to have my needs

> met in a way that worked for me. I could have had opportunities to stand up for myself. (n.p.)

Undiagnosed women do not receive supports and strategies to understand and navigate social situations or sensory challenges that they are experiencing due to neurological differences. Instead, surface behaviors are seen and treated. Without a diagnosis, these women also do not have a community of support from other women who are living in the world with the same (or similar) patterns of strengths and challenges.

Additionally, autistic girls and women are particularly at high risk for domestic violence and sexual assault (Attwood & Grandlin, 2006; Holliday Willey, 2014). Lei Wiley-Mydske (2017) wrote:

> Growing up…I was conditioned early to know that my saying "no" was not an option, certain "atypical" behaviors needed to be eliminated, and being compliant made me "good."[…] In doing so, I opened myself up to become a victim of both emotional and sexual abuse from adults and bullying from my peers. (p. 55)

This can be even more of an issue for late-in-life diagnosed women who, as young women and girls, did not receive the supports to help interpret social cues and sexual dynamics (Hendricks, 2015).

This project narratively explored the schooling experiences of autistic women and examined the ways that interventions (may have) played in their school life. Autism interventions tend to fall into two camps: the behavioral and the constructivist/developmental perspectives. The behavioral camp accounts for the vast majority of both in-school and out-of-school interventions. To understand both the conceptual underpinnings of these different philosophical approaches as well as the kinds of research that is being done around autistic interventions and/or school-based interventions, I conducted a mini-literature review consisting of 20 research articles. A majority of the behavioral intervention studies occurred in school

settings, as ABA is the most widely used intervention in school settings for autistic children (Devita-Raeburn, 2016; Silberman, 2015; Yergeau, 2018). The developmental/constructivist approaches tend to be more strengths-based approaches but occur outside of the school setting in either homes or clinics. These two camps represent very different philosophical framings of autism and the goal of intervention. What is common across both philosophical camps is the silence around gender and race.

Intervention Studies on Autism

Autism intervention studies are similarly dominated by positivist research that measures IQ score, verbal output, and stereotypical behaviors as "improvements" of intervention. There is a distinction here between *intervention* studies and *causation* studies. Causation studies focus on the biological or genetic theories around autism, whereas intervention studies look at the specific clinical or educational supports provided for autistic children and assess their effectiveness.

The behavioral intervention studies represent the most common school-based autism research. Unpacking some of the implications of these ABA studies has real implications for schooling practices for autistic youth. I highlight those implications both in this section as well as the next section, where I outline a DSE approach to inclusive schooling. Given the nature of the constructivist intervention, most of the constructivist studies occurred in family or clinic settings. Both are important to examine as they represent school-based and clinic-/home-based interventions that are very common for many autistic children.

The articles in this section are divided into two different methodological lenses: behavioral and developmental/constructivist perspectives. A behavioral approach includes such methodologies as ABA, Lovaas' Intensive Behavioral Treatment (IBT), and discrete trial

training (Lovaas, 1987). A developmental approach includes the DIR Floortime model (Wieder & Greenspan, 2003) and the PLAY project (Solomon et al., 2007).

Key search terms were entered into the ERIC database. The search terms included *ABA intervention studies,* and *developmental intervention studies*; however, these terms produced an incredibly large data set of behavioral intervention studies. Therefore, articles were further narrowed using two well-respected literature reviews (Brunner & Seung, 2009; Odom et al., 2012), which were published in peer-reviewed journals. Intervention studies that examined developmental approaches are far less researched and therefore harder to find in traditional search engines. One of the leading developmental professional organizations, the Interdisciplinary Council on Development and Learning (ICDL), was consulted for a list of recommended studies (www.icdl.com/research), and additional articles were included that were more recent publications. The limited selection (10 behavioral studies) provided in this review represents a small sample of the current research on behavioral autism interventions; however, the 10 developmental articles covered in this review represent nearly *all* of the current developmental ASD research in publication. Articles were excluded that only included children under school age (under 3 years old) as I was interested in how these studies had implications for schooling practices.

Behavioral Intervention Studies

Each of the studies reviewed in the behavioral interventions aimed to either generalize Lovaas' (1987) original work to school settings or to test if his results extended to children older than 46 months but under the age of 8. The studies reviewed here compared a treatment group in a community setting (intensive ABA) to (one or more) control groups that received an "eclectic" intervention. All seven articles claimed the effectiveness of ABA intervention over an eclectic

approach. Several of the studies followed a group of students for 10 months to 1 year (Eikeseth et al. 2002; Howard et al., 2005; Reed et al., 2007), whereas Cohen et al. (2006), Eikeseth et al. (2007), and Howard et al. (2014) followed up on previous studies to measure progress 2 or 3 years later. All of the follow-up studies pointed to increasing IQ scores as lasting proof that the intensive ABA intervention led to continued long-term growth. The Eikeseth et al. (2007) study, however, did not measure the treatment hours in the control group.

All seven studies showed higher IQ test scores for the behavioral treatment group over the eclectic group; five out of seven of these articles offered significantly more hours of ABA intervention weekly as compared to the eclectic approach. Only two studies (Eikeseth et al., 2002, 2007) offered the same intervention hours between the treatment and control groups. Eikeseth et al. (2007) found that intensive Lovaas techniques produced higher IQ test scores, as compared to eclectic ABA approaches 2 years after intervention. However, the intervention group did receive significantly more training, more team meeting time, and more supervision for teaching instructors, which may call into question their research findings.

Using IQ scores to prove intervention effectiveness should be questioned. For one, IQ tests often fail to capture the capacities and skills of with people with disabilities. Students with expressive language challenges and/or motor planning differences (meaning it may be hard for them to execute a physical action) can underperform on IQ tests (Devita-Raeburn, 2016). Additionally, there is no proof that higher IQ scores lead to improvements in *social* communication and *reciprocal* interaction (Estes et al., 2011). The *DSM-5* (APA, 2013) described that autism is a developmental disorder affecting social and communication domains; therefore, interventions designed for autistic students should target areas of impairment. IQ tests do not address or measure these social areas of communication and thus are an ineffective way to

measure improvement for autistic interventions (Charman et al., 2011). Lastly, IQ scores do not necessarily predict academic achievement (Estes et al., 2011). By relying on IQ scores to prove the effectiveness of an autism intervention, these studies implied that autism is an intellectual disorder. However, it is not (Silberman, 2015). If ABA is positioned as a scientifically supported school-based intervention for autistic students, then effectiveness of intervention should be linked to school success.

Three of the behavioral studies looked more specifically at communication. Two studies in the behavioral group included family involvement. Fava et al.'s (2011) comparison study examined an intensive treatment group who received parent training and a control group who did not receive parent training. The study reported higher test scores using the Vineland Adaptive Behavior Scale in the treatment group. This assessment measures a wider range of skill areas, compared to the IQ test, including communication, daily living skills, and motor skills (Fava et al., 2011). Jones and Schwartz (2004) used a single research design study to measure the effects of siblings as typical verbal models. No standardized assessments were used in this intervention nor was there any mention of how these tasks improved the students' social communication.

Embedded in all of these behavioral studies are two key assumptions. The first is that more hours of one-to-one ABA intervention produce better results. This is a theme among all of the studies—to replicate or to at least come close to Lovaas' (1987) recommended 40 hours of weekly ABA intervention. Lovaas believed that autistic students could not learn from their natural environment; therefore, adult-led structured settings were necessary. The second major assumption is the belief that autistic students must learn discrete skills before engaging in complex thinking or communication (Howard et al., 2014). Lovaas (1987) outlined that compliance, imitation, and reducing self-stimulatory behaviors were to be targeted initially. Only

after these were mastered would treatment graduate to "teaching expressive and early abstract language and interactive play with peers. The third year [of intervention] emphasized the teaching of appropriate and varied expressions of emotions; pre-academic tasks and *observation* learning" (p. 5). In the ABA methodology, students must master basic skills before moving on to social communication interactions and peer relationships.

These assumptions have major implications for schooling and position autistic students as the "other" compared to their allistic peers. Based on these behavioral assumptions, autistic students must receive specialized interventions away from general education classrooms to achieve improved results. By measuring IQ scores as "proof" of improvement via intervention, a majority of these ABA studies buy into a false notion that autism is a disorder of intelligence.

Developmental/Constructivist Intervention Studies

There is a resistance to ABA interventions among autistic communities, DS scholars, and some practitioners. Constructivist or developmental approaches include DIR Floortime (Greenspan & Wieder, 1997), PLAY project (Solomon et al., 2007), and the SCERTS model (Prizant et al., 2003). Constructivist interventions push against a medicalized cure mentality of ABA. The goals of developmental models include strengthening relationships with family members, peers, and teachers, expanding communication systems (both verbal and with assistive technology), supporting diverse and varied sensory systems though non-invasive interventions like occupational therapy. Rewards are never used. Instead, human connection is the goal for sessions (Greenspan & Wieder, 1997; Prizant et al., 2003). These constructivist approaches are very rarely implemented in school environments; therefore, the studies covered in this approach occurred within the family setting or within a clinic. I chose to outline these approaches as a way to illustrate the different philosophical camps of treatment interventions. While they are not

widely used in schools, when families use these programs at home, they can often have an influence on the school lives of their children.

The Developmental Individual Differences Relationship-based (DIR) Floortime model was founded by Dr. Stanley Greenspan and Serena Wieder as an alternative to a behavioral approach to autism interventions. Greenspan and Wieder (1997) published a case chart review of 200 autistic children to look for developmental trends. They reported that

> some children who had been in intensive behavioral programs could master rote academic skills and even do well on IQ tests. However, they lacked the ability for spontaneous, creative affective interchanges with adults or peers and could not generalize or engage in abstract thinking. (p. 31)

In a follow-up paper, Wieder and Greenspan (2005) reported on 16 children from the original review 10-15 years later and found that this select group of teenagers had decreased in autistic symptoms with a comprehensive program, which included regular Floortime sessions. The study stressed the importance of early intervention approaches that incorporate social interaction, sensory integration support, and family training. This article challenged ABA practices that "wait" for children to be "ready" for social communication. However, the methodology of this paper was flawed. Because the selection of 16 teenagers was unexplained, it was not clear how and why these specific students were chosen out of the larger 200. These kinds of idiosyncratic sampling choices undermined the reliability of the research.

Three studies examined joint attention and social reciprocal circles of communication between the child and the parent. Joint attention is the ability of a child to attend to the socially relevant information in the room and is displayed by meaningful social eye contact, pointing, and body positioning (Mundy et al., 1990). Chiang et al. (2016) and Salt et al. (2002) found in their comparison studies that students who received parent-facilitated Floortime interactions displayed higher rates of joint attention than students in the control group. Salt et al.'s (2002) study may

have limitations due to the small sample size of the comparison group (six children). Dionne and Martini (2011) conducted a single-subject study with an autistic teenage boy using DIR Floortime in a clinic setting with his parent. They reported an increase between the pre- and post-intervention video in the numbers of circles of communication (back-and-forth communication exchanges) between the parent and child.

Of the 10 developmental studies reviewed, four were randomized control trials involving parent coaching. Casenhiser et al. (2011) examined the effects of the DIR Floortime methodology on parent-child relationships and reported "significantly greater enjoyment of interactions with their parents and imitated more join attention frames" (p. 233), as compared to the eclectic control. Solomon et al.'s (2007) original work with the PLAY project reported a similar increase in students' social reciprocity after 8-12 months of parent home-based play intervention. Solomon et al. (2014) expanded and confirmed these results in a randomized control trial, which showed that children who received parent-led play-based intervention showed greater increased rates in social interaction but no statistically significant differences in standardized language assessments. This may confirm Casenhiser et al.'s (2015) claim that "standardized assessments often fail to identify deficits in social communication" (p. 846). Pajareya and Nopmaneejumruslers (2011) used randomized controlled trial in Thailand that produced similar results to Casenhiser et al. (2011) and Solomon et al. (2014). They reported that children in the treatment group who received parent-coached interaction at home showed a significant improvement in interactions between parent and child and an overall growth in communication in just 3 months of intervention.

Similar to comparison studies in the behavioral methodology, all of the treatment groups in the developmental studies received more intervention hours or additional parent coaching as

compared to the control group. This points to methodological challenges in measuring intervention models that aim to add something new (such as a parent training) to a typical treatment course. This makes it more challenging for researchers to prove that the intervention itself was the source for student improvement.

Embedded in the developmental studies are two very different assumptions, as compared to the behavioral methodologies. First, strong relationships are essential for long-term meaningful growth in autistic children. Skills need to be taught within the context of meaningful interactions with trusted caregivers or teachers. Building strong relationships with caregivers and teachers helps children to develop internal motivations for communication rather than rely on external motivations such as food rewards (Lovaas, 1987; Moser & Grant, 1965). Developmental models put parent involvement as a keystone to the intervention. In comparison to the ABA articles, every developmental study included an element of parent training or involvement; however, because of the focus on parent involvement, none of the developmental studies took place in school settings. Thus, the influence of this kind of methodology in schooling contexts is limited. Second, developmental approaches believe children must learn and practice the foundations of social communication at any, and every, developmental capacity. In the behavioral model, children are taught discrete pre-linguistic skills such as imitation before moving on to social interaction, whereas in the developmental model, parents and teachers encourage social reciprocal verbal and nonverbal communication for all children. The behavioral perspective implies that students need to be "ready" for social interaction and require a set of pre-skills *before* they can access learning in the way that allistic students can. This mentality goes against a presuming competence stance (Biklen, 1990) and, instead, puts the onus on autistic children to prove their "readiness" for learning.

Developmental approaches come closer to embracing a neurodiverse perspective. At a DIR national conference a few years ago (in November 2018), representatives from the Autistic Self-Advocacy Network outlined ways that clinicians can respect autism and still pursue clinical interventions. The fundamental challenge with developmental approaches is that they continue to reinscribe a particular notion of "normal" development. In DIR Floortime, there is much discussion of "typical" child development. Intervention is aimed at retracing some developmental milestones that are "skipped" by autistic children. Again, the "myth of the normal child" (Baglieri et al., 2011) is propped up in an intervention that measures success by reaching typicality. Both methodologies ascribe to a particular location of autism: "Autism research operates on the hope that there will be no autistic future" (Yergeau, 2018, p. 19).

Another common theme across behavioral and constructivist intervention studies was the way that many of the researchers described (*or did not* describe) their participants. Fourteen of the 20 articles did not mention the gender or race of the participants. In the studies that did mention gender, there was an underrepresentation of girls. Eikeseth et al.'s (2002) study included 19 boys and 6 girls; Fava et al.'s (2002) study included 19 boys and 3 girls; and although the Wieder and Greenspan (2005) article made no mention of overall gender statistics in their sample, the four vignette students who were highlighted in the article were all male. None of the 20 articles explicitly discussed African American or Latino students of any gender, and Pajareye and Nopmaneejumruslers (2011) conducted the only study to mention Asian students explicitly as their research came out of Thailand. All of the studies, with the exception of two (Wieder & Greenspan, 2005; Dionne & Martini, 2011), involved students under the age of 8 years. This small sample of articles from autism intervention studies illustrated both a lack of diversity in the

kinds of research that happen around autism interventions in schools and at home, both in terms of gender, race, and age, as well as its overwhelmingly positivist and behavioral slant.

DSE-Informed Inclusive Stances toward Autism and Schooling

What many of the intervention-based researchers conflate is the difference between a physical educational *space* and an educational *stance*. Even if a student is placed in a general education or mainstream classroom with their allistic peers, many DS scholars would argue, this may not be inclusion. Many articles in the behavioral methodology above (Cohen et al., 2006; Eikeseth et al., 2002; Howard et al., 2014) understood special education as a kind of delivery model. A student is placed in a general education classroom and is pulled out by a therapist or specialist to receive ABA sessions and then returned to the general education class. Special education as an education model comes from a behavioral lineage, which measures differences as deficits (Erevelles & Minear, 2010; McDermott & Raley, 2008; Sleeter, 1987). This model falls short of what many DS scholars would describe as inclusion (Baglieri et al., 2011; Erevelles, 2011; Valle & Connor, 2011).

Douglas Biklen (2006) coauthored an article with Jamie Burke, an autistic teenage boy who uses assistive technology to communicate. Burke explained that successful inclusion hinges on the attitudes of the teacher who see him as capable, a teacher who presumes his competence (Biklen, 1990), and can adapt supports to fit his unique learning and processing needs:

> Teachers must be willing to not just give me a desk and then leave me to fill the chair. I need to be asked questions, and given time for my thoughtful answers. Teachers need to become as a conductor, and guide me through the many places I may get lost. (p. 172)

Exposure to general education curriculum without meaningful adjustments to curriculum does little to dislodge the location of special education in general education classrooms and continues to construct the disabled student in deficit lenses (Baglieri et al., 2011; Biklen, 2005).

Additionally, when support services are fixed to particular locations and spaces (special education classrooms receive certain kinds of support such as assistive technology, whereas general education does not), students can be pushed to choose between getting the kind of therapeutic supports they may need and having access to a general education curriculum that provides academic challenge. When reflecting on her educational experiences as an autistic woman, Katie Levin (2017) described falling between the cracks of special education and mainstream (general) education:

> I needed the support of special education, but not the remedial level work [...] when I was mainstreamed into harder classes, I often had a hard time keeping up…. It was either/or: harder work with not enough support, or more support with work that was too easy. (pp. 50- 51)

When services are tied to segregated settings, students can be placed in a "damned if you do, damned if you don't" situation.

DSE scholar and teacher educator Paula Kluth's (2010) work has been dedicated to inclusive practices for autistic students and believes that all children are capable of meaningful inclusive education. She urged educators to take a strength-based approach towards students and to center students' interests and passions as thematic curriculum projects. It is common for autistics to have an area of special interest, and rather than frame these idiosyncratic passions as periphery or distracting to classroom learning (Barron & Barron, 1992; Jackson, 2002; Tammet, 2007), teachers should see these passion topics as rich curricular areas of interest and position students as experts (Kluth & Schwarz, 2008, p. 37). Kasa-Henrickson's (2005) research examined teachers who take a capacity-oriented approach towards nonverbal autistic students. She found that capacity-oriented teachers embraced more expansive definitions of student participation and interpreted rocking in place or flapping their hands as forms of expression rather than expressions of non-compliance (p. 66). All students benefit when classroom

curriculum reflects student interests and there are flexible definitions of participation (Kasa-Henrickson, 2005; Kluth & Schwarz, 2008).

Creating literacy access for autistic students and other students with disabilities is an issue of "citizenship," argued DSE scholar Christopher Kliewer (2008). When students are denied access to literacy, which Kliewer defined as "modes of visual, orthographic, or tactile expression" (p. 20), teachers are segregating these students to the status of "alien" or "squatter" in the classroom (p. 20), which structurally excludes them from meaningful classroom participation. All too often, teachers adopt a traditional "ladder model" of literacy, which understands literacy development to be a linear progression. Students first must master phonics instruction consisting of drill and skill before they can move on to more meaning-making literacy activities such as writing, storytelling, or read-alouds (Kliewer et al., 2004, p. 378). Adhering to strict phonics-based frameworks adversely affects autistic students who often have strong sight-word reading skills and may not develop reading through phonics-based instruction (Biklen, 2005; Kliewer, 2008). When teachers adopt a one-size-fits-all approach to literacy instruction, autistic students are all too often assumed to be "naturally illiterate" (Kliewer et al., 2004, p. 379; Kliewer, Biklen, & Kasa-Hendrickson, 2006) and thus are stuck on the lower phonics rung.

Kliewer et al. (2004) conducted a 2-year ethnographic study of the inclusive literacy practices in nine preschool and kindergarten classes across five different educational settings. The research team was interested in documenting the ways that teachers fostered literate citizenship practices for students with significant disabilities in inclusive classrooms, including autistic students. Researchers found that effective inclusive teachers were able to take a capacity-oriented approach towards students with disabilities. Rather than adhering to a linear model of literacy (Kliewer & Biklen, 2001), these teachers encouraged all students to participate in

meaning making through multiple forms of literacy practices, including sign making, storytelling, audio recording, and pretend play (Kliewer et al., 2004). By incorporating multiple forms of expression and knowledge production, these teachers were embracing a multimodal form of literacy instruction (King-Sears & Evmenova, 2007). Multimodal pedagogies combine one or more modes of communication (speech, gestures, auditory, writing, music) (Elder-Hinshaw & Manset-Williamson, 2006; Mills, 2010; Naraian & Surabian, 2014) to allow for multiple ways of comprehension and expression.

Multimodality is a key component in Universal Design for Learning (UDL) principles. UDL understands that there are multiple ways that students can express, participate, and build knowledge and that all students should be given equal access to the curriculum, regardless of their learning styles (Capp, 2017). UDL has been embraced by DSE scholars. Michael and Trezek (2006) understood UDL to be an issue of "educational justice" (p. 312):

> By employing universal design instructional strategies, we, as educators, can provide equal access to complex curriculum typically only afforded to those students who read and write well enough to access the content and provide demonstration of knowledge and literate thought via these traditional methods. (p. 316)

DSE researchers and educators *expect* and *plan for* diverse learning styles and needs rather than *adapt after*. Chapter III builds from the work of these DSE scholars, particularly the ways that multimodal forms of knowledge production are planned for and privileged as generative forms of sense making.

Chapter III: METHODOLOGY

This project is a narrative inquiry that explores the schooling experiences of three autistic women. The basis of this inquiry is that autistic women have important stories to tell about their school experiences, stories that have all too often been ignored or eclipsed by a field, i.e., positivist autism research, that constructs autistics as a problem to be solved, and by a category—autistic—that is presumed to be male. By minimizing the voices of autistic women, current research has captured only a "partial" or "inadequate" (Creswell, 2007, p. 40) picture of autistic women's schooling experiences and the role that gender plays in these educational settings. By centering autistic women, I locate this project within a social justice qualitative stance (Denzin & Lincoln, 2005) to address the silencing of women's stories in autistic research.

Overall Research Design

As a DS researcher, one of the orienting commitments of this project is that I presumed competence of my participants (Biklen, 2005) and, to do so, I accounted for and responded to the various ways in which my participants preferred to communicate. In addition to the more traditional forms of ethnographic data collection such as interviews, field notes, photo documentation, and participant observation (Bogdan & Biklen, 2007; Spradley, 1980), I included data collection that privileged their sense making. Multimodal data included drawing and/or collage (Tay-Lim & Lim, 2013), movement (Castrodale, 2018), and visual media elements such as television or YouTube clips (Pink, 2011). In this chapter, I lay out the rationale for a narrative inquiry and how this stance aligned with DS tenets. I also outline how I approached this multimodal project and the pilot studies that helped inform my current dissertation research, which asked the following research questions:

How do autistic women author their schooling experiences?

1. What do autistic women share about their schooling experiences?
    a. What experiences do they identify as supportive and/or challenging? Why?
    b. What is the significance of intervention in their school lives?
2. How do autistic women express their identities?
    a. What understandings of disability and normalcy do they disclose?
    b. How do they express their gender identity?
3. How are relationships made significant in autistic women's lives?
    a. What kinds of relationships with staff and peers do they disclose?
    b. How do they navigate and define their relationships?

Qualitative Inquiry and Disability Studies

The majority of autism research comes from a positivist and quantitative epistemology. As discussed in Chapter II, schooling studies that focused on autistic youth were dominated by intervention studies that measured success by standardized tests (IQ) tests, control and intervention groups, and medicalized diagnostic criteria (Autism Rating Scales). These kinds of studies were part of a larger trend in educational research that prioritized *evidence-based practices* (EBP) and *scientific research* when, in reality, these were "code words for randomized experiments" (Berliner, 2002). ABA approaches fit perfectly into this kind of research approach; thus, a majority of the field of educational research on autism has been dominated by ABA intervention studies.

Intervention studies that stress recovery, or degrees of improvement away from autistic expressions, adopt a medical model of disability that locates the problem in the body of the autistic person (Barnes, 1991; Hahn, 1988; Oliver, 1990, 1996). Autistics are very rarely

included as knowledge producers in these research frameworks; instead, autistic bodies are studied, and teachers and parents are interviewed as the "knowers" of their students' and children's schooling experiences. The social model of disability (Oliver, 1996), and more specifically the political/relational model of disability (Kafer, 2013), unpacked the ways in which the medical communities attach deviance and deficit to the disabled body and create space for disability identities. A qualitative research design was essential for this project as I explored the ways that these women constructed meaning from their schooling experiences rather than quantitatively measuring interventions from an outsider/expert perspective.

Mike Oliver (1997) called for DS researchers to adopt an emancipatory research methodology, which extends beyond a surface investigation of a problem or an injustice in the disability community. Instead, researchers must be aligned with their participants to reach a shared goal (Oliver, 1997, p. 188). Oliver was critical of non-disabled academics that built careers via research *on* disability communities rather than *with* disability communities and who did little to change the lived reality of injustice in those communities (Barnes & Mercer, 1997; Goodley, 2011; Oliver, 1997). My project was oriented around an emancipatory research stance; to do so, my design was flexible so I could adapt and adjust to participants' goals, preferences, and communication styles. Narrative inquiry aligned itself well with these research aims and my research questions.

Narrative Inquiry

Narrative inquiry is both a method and a theory that explores a phenomenon (Clandinin, 2013) by capturing and collecting the "detailed stories or life experiences" (Creswell, 2007, p. 55). Narrative researchers believe that all humans lead storied lives, and it is through stories and the telling of our own stories that we make meaning of our experience (Bruner, 1986).

Researchers working from a narrative inquiry stance use open interview techniques ("Tell me a story about ____"), artifacts, participant observation, and visual images to co-construct a story of a participant's lived experience of a particular phenomenon (Schaafsma & Vinz, 2011). Due to its extensive time commitment, narrative inquiry is most effective when working with a small group of participants so that the researcher can dive deeply into the individual sense making of the participants (Creswell, 2007). In the past 2 decades, narrative inquiry has been more popular as a research design, particularly in the field of education, as it has the "potential to present complexities and ways of acknowledging the influence of experience and culture on human learning and knowledge construction" (Schaafsma & Vinz, 2011, p. 2). I outline the emic stance of narrative inquiry, the role of experience, the relational stance of the researcher towards participants, and the theoretical framings of story to situate why this particular methodology was essential to my project. I also include critiques of narrative inquiry and ways that I plan to address those critiques in my research.

Emic and etic. Narrative research privileges insider perspectives and therefore is aligned with an emic viewpoint of knowledge production (Goode, 1992). Research that values emic perspectives positions the insider perspective as the expert one, and the research attempts to "capture participants' indigenous meanings of real world events" (Yin, 2010, p. 11). In contrast, the etic perspective comes from the outsiders who position researchers as external from the environment and therefore objective. Historically, the medical and scientific fields have maintained an etic perspective that positions the researcher as expert observer. DS scholar David Goode (1992) explained:

> Clinical frameworks tend to be exclusively etic and explicitly oriented to finding and eradicating flaws through therapy, treatment, or training of some sort. Their descriptions of behavior *inevitably* find no value in deviation from accepted behavioral norms. The

> emic perspective necessarily emphasizes, in contradiction, the value and creativity of deviant behaviors. (p. 198)

The epistemological stance of the positivist research that dominates the autism field (Asperger, 1944; Baron-Cohen, 1987; Kanner, 1943; Lovaas, 1987) is predicated on an etic orientation and devalues the experiences and knowledges of autistics.

A narrative research design that privileges an emic perspective is epistemologically aligned with a DS/DSE stance. DS autistic scholar Melanie Yergeau (2018) argued that autistic "storying as a methodology" (p. 42) is a radical act that pushes against the dominant constructions of autistics as non-rhetorical and involuntary. She pointed to the example of the prevalence of "parental poop talk" (p. 2), where parents blog in extremely graphic detail about their autistic children's bathroom habits. "These shitty narratives—rhetorical commonplaces that author autistic people as victim captives of a faulty neurology, as rhetorically degraded and rhetorically suspect. In these constructions, our shit holds more rhetorical power than we do […]" (p. 3). "Shitty narratives" of autism dominate, Yergeau (2018) explained, because they confirm a long-held stereotype of autistics as "unknowable, as utterly abject and isolated and tragic, as a figure whose actions are construed less like actions and more like neuronally willed middle fingers" (p. 3). Narrative inquiry allowed for a flexible research design that could adapt to and accommodate various communication preferences. By storying women's autistic lives through narrative inquiry, this project strongly challenged ableist constructions of the autistic as mindblind (Baron-Cohen, 1995) and incapable of having the intersubjectivity to tell their own stories.

My framing of narrative inquiry came from Jean Clandinin and her colleagues (Clandinin, 2013; Clandinin & Roseik, 2007; Connelly & Clandinin, 2004). Clandinin (2013)

made a key distinction between a narrative inquiry and simply "telling" or writing the results of a research study in a storied format. She defined narrative inquiry in the following way:

> People shape their daily lives by stories of who they and others are and as they interpret their past in terms of these stories. Story, in the current idiom, is a portal through which a person enters the world and by which their experience of the world is interested and made personally meaningful. Narrative inquiry, the study of experiences as story, then, is first and foremost a way of thinking about experience. Narrative inquiry as a methodology entails a view of the phenomenon. To use narrative inquiry methodology is to adopt a particular view of experiences as phenomenon under study. (Connelly & Clandinin, 2006, p. 375)

Clandinin (2013) outlined two essential elements of narrative inquiry: the particular framing of experience influenced by the work of John Dewey, and the transactional or relational model between participants and researchers.

Experience. John Dewey (1938) understood experience to be comprised of both interaction—our relationships with our surroundings—and continuity, i.e., experiences have collective influences on the future and are continuous (p. 43). Narrative inquiry understands experience as three-dimensional consisting of space, temporality, and sociality of participants. "Narrative inquiry is a way of understanding experience. It is collaboration between researcher and participants, over time, in a place or series of places, and in social interaction with milieus" (Clandinin & Connelly, 2000, p. 20). Framed within this view of experience, the focus of narrative inquiry is not only on individual's experiences but also on the social, cultural, and institutional narratives within which individual's experiences are constituted, shaped, expressed, and enacted (Clandinin & Rosiek, 2007).

Relational stance and researcher role. The role of the researcher in a narrative inquiry project is not neutral; instead, a researcher is an active participant in the creation and production of the participant's narrative (Clandinin & Rosiek, 2007). Rather than observing from an outsider perspective, the researcher is a participant and "lives alongside" participants (Clandinin, 2013,

p. 45). Researchers should go where participants want to take them and, in so doing, researchers "enter spaces that are important to participants (p. 45). Clandinin described this dynamic as having a "relational stance" (p. 16) with participants. This means that trust needs to be built over time so that participants can feel safe to be vulnerable (Douglas & Carless, 2009).

Researchers should ask themselves how they can be of service to participants. Jean Clandinin's work examined the lived experiences in schools, particularly the lives of teachers (Clandinin, 1983; Clandinin & Connelly, 1986; Connelly & Clandinin, 1988). In collaborating with participants, Clandinin worked to assist the teacher in classroom activities, attended professional development training with the teachers, and also shared many meals together to develop a relational stance with participants. For my project, being of service to participants included sharing a meal, drawing together, walking in silence, listening to music, sending texts and selfies, playing Candyland, and making connections to support organizations. Through a relational stance, hierarchies between researcher and participant are challenged and researchers move into positions "alongside" participants (Clandinin, 2013, p. 141). I continue to explore my own relational stance later in this chapter.

Narratives and stories. Narrative researchers believe that humans "lead storied lives" (Clandinin & Rosiek, 2007, p. 6). It is through stories that communities construct and share their identities (Riessman, 2008) and move from individuals into collectives (Frank, 2010). Stories and narratives are intrinsically linked. Different narrative researchers use these terms in different ways. I found Kim's (2016) framing to be helpful. She explained that a narrative is a partial story, whereas a story is a "full description of a lived experience" (p. 9). For Kim, "story is clearly a higher category than narrative as the later constitutes the former" (p. 9). Stories are

constructed from narratives and have a beginning, a middle, and an end, but do not have to be chronologically oriented (Abbott, 2002).

Psychologist Jerome Bruner's framework of stories and thinking is well cited among narrative researchers. Bruner (1986) argued that there are two kinds of thought that humans use to make sense of their experience: paradigmatic and narrative. Paradigmatic or logical-scientific thought appeals to a mathematical style of description, which results in a formal scientific organization of the world and universal truths (p. 12). Narrative knowing is where humans make sense of their experiences through stories. Narrative modes of thought create opportunities to unpack the complex and conflicting aspects of human experiences (Bruner, 1986). Both forms of thinking are important, but they serve very different purposes:

> The paradigmatic mode offers the power of prediction in that it sets up and tests hypotheses about the nature of reality. In contrast, the narrative mode organizes the complex and often ambiguous world of human intention and action into a meaningful structure. (Adler, 2008, p. 423)

Both of these modes of thinking have very different ways of addressing credibility that are explored in more detail in later sections (see validity, trustworthiness, and ethics).

Critiques of narrative inquiry. Critics of narrative inquiry research have argued that validity and trustworthiness are major issues for narrative researchers. If sense making is privileged, what happens when, for example, two different stories conflict? In the fields of anthropology, psychology, and film, this is referred to as the Rashomon effect (Kim, 2016). The term comes from a 1950 Japanese movie that depicts an event from four different perspectives. The movie ends with no resolution, no agreed-upon truth. The line of fact and fiction is blurred. Many narrative researchers embrace this "borderland" space (Clandinin, 2013) and understand narratives as "an unstable mixture of fabulation and actual experience" (Ricoeur, 1992, p. 162).

Instead of aiming to resolve this tension, Clandinin and Connelly (2004) urged researchers to name and explore issues around conflicting stories. The only way to account for these blurred lines is to name them transparently (Freeman, 2017). Lieblich et al. (1998) argued that instead of traditional notions of validity, narrative research should be assessed for its "width." Width refers to the depth in which researchers have made their decisions, analysis, field notes, and theories transparent throughout the process so that a reader can walk through their interpretations.

Another tension for critics of narrative inquiry are issues around ethical concerns between researcher and participant. Kim (2016) explained that narrative researchers need to be careful about engaging in "backyard research" (p. 246). When participant/researcher relationships are prioritized, it can be tempting for researchers to recruit participants from their own communities or workplaces. While this may provide some strengths for the research in that there is already established trust, it can also provide ethical quandaries. For example, Kim detailed the moral dilemma in being asked to participate in a study at her home university. The researcher wanted to explore the experiences of faculty of color on campus. While the research project was important, the intimacy of the university and the small number of faculty of color on campus compromised Kim's anonymity and affected her ability to be honest about her experiences. It also brought up potential issues around job security if her stories reflected badly on the university. Ethical concerns are further complicated when narratives are co-constructed but participant identities are anonymous. Tensions around how to both protect anonymity while also acknowledging the co-construction of a narrative remain much discussed but are ultimately unresolved tensions in narrative research (Riessman, 2008).

Pilot Studies

Before beginning my dissertation research, I engaged in two pilot case studies where I worked with and interviewed autistic or disabled women. These research opportunities helped me to come to my current methodological framing for this project. I narratively describe each pilot study and highlight the ways that my framing of research evolved through these particular projects.

June

The first pilot study came out of Professor Nancy Lesko's course, where I interviewed a teenaged young woman who attended a private school for autistic students. Over the course of the Spring 2017 semester, I engaged in 10 interviews with June (a pseudonym to protect her privacy). These interviews were audio-recorded and later transcribed. I was inspired by the emphasis on poststructuralist feminist theory in the course, and this was the first project where I began to experiment with feminist epistemologies. My intention for the project was to follow in the tradition of feminist scholar Patti Lather (2007), because she explained her role as a researcher is to be committed to "exploring the textual possibilities for telling stories that situate researchers not so much as experts 'saying what things mean' in terms of 'data,' the researcher is situated as witness giving testimony to the lives of others" (p. 41). A feminist epistemology was essential to the project as it questioned "whose knowledge is being given priority and coverage" because "the case can be made that what is seen as knowledge is that which is defined by men, who are defining male experience as universal on the basis of all-male samples" (Coffey & Delamont, 2000, p. 30). In this project, I was drawn to the notions of gender that June constructed. In one interview, I asked June, "Do you think of yourself as a girl? A woman?" and June answered, "A young lady" (June, personal interview, February 2, 2017).

The interviews with June were conversational in style; however, after the first two interviews, I noticed that June seemed anxious, almost as if I were quizzing her. I realized that perhaps adding a multimodal element to the interview process would add a depth to the conversation, allow for multiple forms of communication styles, and be more respectful to her own individual communication differences. Multimodality considers language to be only one form of representation among others, such as gesture, sound, images, and music (Archer & Newfield, 2014, p. 1). Multimodality has long had connections to DSE and Universal Design in Learning (UDL), i.e., the idea that all students can learn when learning differences are expected and planned for in advance (Meyer et al., 2014; Michael & Trezek, 2006). Multimodal pedagogies combine one or more modes of communication (speech, gestures, auditory, writing, music) (Elder-Hinshaw & Manset-Williamson, 2006; Mills, 2010; Naraian & Surabian, 2014), so that students can have multiple forms of entry and expression to materials and curricular concepts.

To delve a bit more deeply into June's reflections and interpretations of gender roles and stereotypes, we viewed and discussed an episode of her favorite TV show, *Drake and Josh* (Schneider, 2005). This allowed June to reflect on something of interest that explored dating and gender dynamics in a more concrete way. It also gave us the opportunity to watch and re-watch different parts of the TV show so that June could review dialogue that she experienced as too fast. Through working with June, I became increasingly aware of the limitations of strict verbal interview techniques.

Abby

The second pilot study was conducted in the Spring of 2018, for an Ethnography course at the New School with Professor Terry Williams. For this project, I worked with a young

autistic woman with the pseudonym of "Abby." My goal for the project was to explore different kinds of methodologies to see how I could engage Abby in a more participatory data collection that privileged other ways of knowing that extended beyond verbal communication. The ethnographic project covered a 2-month span and consisted of eight "interview" sessions that lasted between 30 and 50 minutes. In one session, I followed her lead and asked her to show me what she liked to do in the school building where the project was based. The session began with Abby saying she wanted to make instant oatmeal. What followed was me joining Abby as she made oatmeal for 35 minutes. Each of her movements in the process was slow and intentional. Between each step of the sequence were many minutes of silence and repetitive motion. For example, she would open the oatmeal, stand in front of the cabinet that contained the bowls, rock back and forth on her toes, and hum for approximately 3 minutes before grabbing a bowl from the shelf.

This experience of making oatmeal was incredibly generative for me and left me wondering about nonverbal forms of communication and their meaning. In this scenario, I was struck by the silences and the passage of time. As a researcher, how would I account for silence? What is the meaning of these silences for Abby?

> Comprehending a spoken text can be a very demanding task: however, trying to capture what is meant by an unspoken text involves the recipient not merely in an effort to infer what is being communicated through absence of words, but also in perceiving the social meaning of the use of silence in the specific communication instance. (Dendrinos & Ribiero Pedro, 1997, p. 215)

These moments left me wanting to understand more about how Abby constructed these silences. How did the passage of time feel for her?

As the project continued, I expanded my data collection to include more multimodal and nonverbal forms of data collection that extended beyond the verbal interview. These methods

included drawing, collaborative internet searches, walks, eating, and dancing and singing together to a YouTube playlist that Abby constructed. Body movements and dancing are strong and powerful communication tools. Dancing is an important part of disability communities; it creates community and transforms the body, pushing notions of what normative bodies are supposed to do and behave. DS scholar Stacey Clifford Simplican (2015) traced the history of dance and disability: "Dancing is important for disability rights activists because it embodies an expression of a life well lived" (p. 131). Through dance, alliances can form and expression can be shared in "non-cognitive ways" (p. 130). From a DS stance, I saw these moments of joy and elation to be transgressive to the traditional power relations of *researcher* and *subject*.

In another session, I asked Abby to show me what she liked to do on the computer. She led me to the website Ebay, where one can buy and sell almost any item. Her items of choice were discontinued matchbook cars and planes. She shared with me that she would spend every day after school looking at them, pricing them out, and watching as their prices increased and decreased. Below are some screenshots of her most watched items (Figures 1 and 2).

Figure 5. *Matchbox Skybusters Mission Pack*

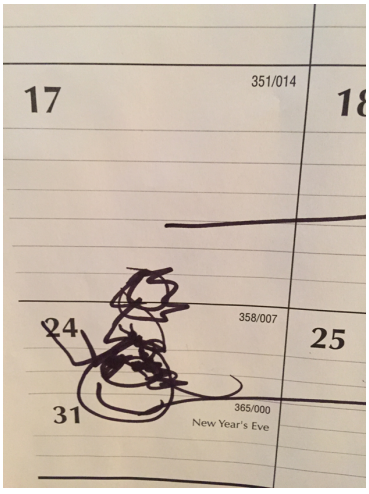
Figure 6. *Matchbox Desert Pack Cars*

Because of the limitation of the pilot study, I was not able to learn more about Abby's collections, but I was left wondering about the value and place these objects had in her life. How

did she display these items? How were they organized? I knew that in later studies, I wanted to think more deeply about the role of these kinds of beloved objects and collections. I knew that in my dissertation research I wanted to privilege my participants interests as a major organizing aspect of the research activities.

Drawing was another form of expression for Abby, but it was one that I was late to realize was generative in her meaning making. During one session, she described her love of parties and family celebrations. Below is a small doodle she made on a wall calendar to mark an upcoming event (Figure 7). She named the drawing "Party Hat." At the time, I did not think much of the small drawing. It was only later, when I began to analyze the collection of artifacts, that I retrospectively saw the potential of expanding on drawing as a way to explore how Abby saw herself, what she valued, and how she expressed these opinions and preferences. Her love for parties and celebrations was a reflection of how much she loved and felt connected to her family, their celebrations, and their rituals. It helped me to better understand her role in her family structure and to create webs of meaning (Wibben, 2011) in her social-emotional relationships.

Figure 7. *Abby's "Party Hat"*



June and Abby taught me a great deal about research design, researcher and participant relationships, and the limitations of verbal interviewing. In the next section, I outline my participant criteria and my data collection plan for my current research project. This data design was heavily influenced by my pilot studies with June and Abby.

Instruments and Procedures

Data collection included ethnographic methods such as reflective field notes, "narrative" memos, participant observations, multimodal interviews, and lightly structured interviews (Bogdan & Biklen, 2007; Emerson et al., 2011; Kim, 2016; Wengraf, 2011). As a DS researcher, I privileged multiple forms of expression and knowledge production and incorporated multimodal forms of expression to narratively understand these participants' gendered schooling experiences (Clandinin, 2013; Kim, 2016). Standards of validity, reliability, and trustworthiness were explored through a narrative inquiry stance.

Participants and Site

This dissertation project was an in-depth narrative research with three participants. Criteria for selection included participants who were adults and had recently graduated from school programs (in their 20s). Included participants identified either as a woman or a non-binary autistic who was raised as woman. The participant pool represented different racial and ethnic categories so that the study was reflective of racial diversity within the autistic community. Participants needed to either have an official autism diagnosis or identify as autistic. The educational backgrounds of participants varied between public, private, self-contained, or inclusive settings.

In establishing my criteria for recruitments of my participants it was important that I allowed for self-identification both in the gender and diagnostic categories, considering the ways

in which women are often misdiagnosed. If a participant identified as non-binary, due to the focus of this project on women's experiences in schooling, it was important that the individual be raised as a woman/girl during their school years. As a DS researcher working with concepts from feminist and queer theory, I acknowledge that medical categorization and identity categories are important for issues of access, but also trouble the ways they are constructed as binary constructions of abled/disabled, autistic/allistic, and woman/man.

To get a fuller narrative history, I interviewed parents of participants. Interviewing the various actors in a web of networks is a common practice in narrative and ethnographic research (Wibben, 2011). Family member interviews were conducted with the permission of my participants, and two of my participants were present during the parent interviews. DS scholars trouble the notion of independence, arguing instead that, in fact, we are all interdependent and part of large social and care networks (Kittay, 2011; Mingus, 2017; Piepzna-Samarasinha, 2018). Independence should therefore be measured by a person's ability to make decisions about their own lives rather based on the levels of supports they may need (Caldwell, 2014). Including parent and family perspectives acknowledges the relational way in which experiences are co-constructed and shared within trusted care communities (Casper & Talley, 2005; Ferguson, 2001).

Participants were recruited using purposeful sampling and through established professional networks. Because I have worked in the field of education, specifically with students with autism for 14 years, I have contacts with local organizations, past students, and activist connections. After receiving full IRB approval in July 2019, I shared my IRB recruitment email with various professional networks, including old colleagues and various activist-oriented circles committed to inclusive education practices. Within a few weeks, I heard back from two

interested participants, Kelly (featured in Chapter IV) and Zula (featured in Chapter V). I connected with Jordyn's mother, my third participant (featured in Chapter VI), at an academic talk presenting a speaker whose research focused on autistic girls. Jordyn had attended the school where I worked for many years. I had never been Jordyn's direct teacher, but I was familiar with Jordyn and her family through my role as a staff trainer at the school. When Jordyn and I began collaborating on this project, it had been 8 years since she had last attended the school. My familiarity with Jordyn's past schooling experience and my previous relationship with her and her family added a layer of intimacy to my work with Jordyn; however, because Jordyn was no longer a student at the school, I did not believe I ran the risk of engaging in "backyard research" (Kim, 2016, p. 246). I explore my relationship with Jordy and her family in more detail in Chapter VI.

The next three chapters give a detailed picture of each of the participants' lives and their school experience. I introduce them briefly here. Chapter IV is dedicated to sharing Kelly's narrative. Kelly is a 28-year-old White autistic woman who works as a coder for a health care company where she develops apps and software. Kelly is considered a late diagnosed autistic woman. She was raised by her mother and began self-diagnosing at 18. She received a professional autism diagnosis at 19 just as she entered college, where she studied art and biology. Kelly enjoys drawing, coding, playing video games, and spending time with friends. She has a large network of neurodiverse friends and has been part of the autism advocacy movement since she began self-identifying as autistic. Kelly attended public schools throughout her K-12 years and did not receive any support services.

Chapter V is dedicated to Zula who is a 26-year-old White autistic woman who received an autism diagnosis as a toddler. Zula was raised by her mother and her grandparents. During her

school years, Zula attended special education public school programming, which meant that her class time was spent in specialized special education classrooms with other students with disabilities. Zula lives with her husband, Ben, in an apartment close to her mother. They have been married for 3 years. She enjoys spending time with her mother, her husband, and her four cats. Zula has worked for the last few years at a thrift shop where she sorts and organizes clothing and enjoys drawing favorite cartoon characters, playing phone-based word games, and going to the movies with her mother and her husband.

Chapter VI shares Jordyn's story, a 26-year-old Black autistic woman who lives with her parents and her autistic brother. Jordyn received an autism diagnosis at the age of 3 only after continued advocacy from her parents. Before the pandemic, Jordyn spent her days attending an adult program for people with disabilities. Jordyn is a very visually oriented person who enjoys looking at photographs and taking pictures on her phone. She is a private person who shows strong affections and connections with her close circle of family members. Throughout her schooling years, she attended private school programs designed for students with disabilities, specifically autistic students. Jordyn communicates with short phrases and gestures. On weekends, Jordyn enjoys going grocery shopping or trips to the local dollar store to purchase art materials. She also enjoys playing the board game Candyland.

I began working with my participants in September of 2019 and ended the data collection process in June of 2020. I conducted interviews and multimodal activities in an environment that the participants chose. Conducting interviews in the naturalized setting of a participant is important to combat some of the power dynamics between researcher and participant (Castrodale, 2018; Clandinin, 2013) and allows the researcher to "live alongside" the participant's preferred locations (Clandinin, 2013, p. 45). This project was not place- or site-

specific. I was not, for example, doing my research at a particular school or work location. I was open, however, to whatever social space my participants wanted me to enter.

Each participant preferred a different location based on comfort and ease. Because Kelly had a demanding work and social schedule, it was easiest for her to meet at a café close to her work approximately one to two times per month. Zula preferred a more consistent schedule. We met weekly on Mondays directly after her work at the thrift shop. On most occasions, we met at her preferred Starbucks that was located on the corner of her mother's apartment. I met with Jordyn in her family home on evenings. Generally, we would spend time together in her bedroom working on various multimodal art projects or playing Candyland. I would often visit with Jordyn's mother Ada in the family kitchen.

Data Collection and Multimodal Expression

I incorporated and designed data collection techniques that centered my participants' preferred modes of expression. This included drawing, collage, multimedia clips from TV and YouTube, and artifacts. It also included lightly structured interviews (Wengraf, 2011). It was important that my methodology be flexible and could adapt to each participant's preferences. Establishing a relational stance towards my participants meant that not every activity or hour needed to result in concrete data collection captured on film, photo, or transcription. I wanted to make space for mutual joy in this project because I saw this as an essential part of emancipatory research and prioritized this as a DS researcher (Oliver, 1997). Also, as the research space evolved, participant interests evolved as well. In a research study examining the experiences of disabled faculty members, DS researchers and disabled scholars Prince and Kerschbaum (2016) explained the importance of *planning for* rather than *adapting to* disability.

> Disability crips methodology. In other words, when disability is assumed to be an important part of the qualitative interview situation (rather than something external that "enters" the situation and then must be accommodated or compensated for), the interview's normative framework is both exposed and challenged. (p. 20)

Selection of multimodal approaches were co constructed with my participants in a narrative relational approach (Clandinin, 2013). In the next sections, I outline several data sources that we used during our research, including drawing, video elicitation, and artifacts to privilege the individualized sense-making of particular participants.

Drawing, collage, and visual representation. Participatory visual methodologies such as drawing, and collage created opportunities for participants to share their experiences in their own way without relying on verbal communication. Visual methodological approaches have been used with children to explore their rural upbringing (De Lange et al., 2012), and their literacy practices (Finley, 2008; Kendrick & McKay, 2004; Thomson, 2008). Drawing as a form of data generation has also been used in research with adults. Theron (2008) used drawing to examine the experiences of teachers, and Smith et al. (2005) used drawing methodologies to explore how parents viewed themselves. A team of DS researchers used drawing as a way to illustrate their collective biographies and memory stories of normativity and difference; they found that drawing was a powerful reflective process (De Schauwer et al., 2018).

Nonverbal forms of representation are important to include in research with autistic participants as verbal communication is often challenging for autistics. Impairments in verbal communication are both part of the official medicalized diagnosis of autism (APA, 2013) as well as an area of challenge identified by many autistics (Bascom, 2012; Sequenzia, 2012; Yergeau, 2018). DS researcher Douglas Biklen (2005) featured the paintings and writings of Larry Bissonnette in his qualitative research study with autistics who type to communicate. As an

autistic painter, Bissonettee sees his artwork as a way to communicate with the allistic (non-autistic) world: “Knowledge and learning of art have allowed my abilities to soar out of an airfield occupied by people who don’t have disabilities” (quoted in Biklen, 2005, p. 161). Art became an important medium of expression and a way for him to share his perspective of himself and the world. Biklen (2005) featured Bissonnette’s paintings and writings, as they were his preferred form of representation. More recently, Elizabeth Miller’s (2016) research with adults with aphasia challenged linguistic expectations of verbal interviews. Her research techniques included gestural communication such as pointing and drawing.

In designing my study, I had planned to engage in drawing and collage activities as a way to engage my participants in conversations around gender representations. I had planned to ask my participants to draw a self-portrait and then engage in a follow-up about the drawing. After asking a participant to draw in response to a particular prompt (Can you draw a self-portrait?), I wanted to engage the participant in a verbal or written response to the drawing, also known as a “draw and write” approach (MacGregor et al., 1998; Mitchell et al., 2011; Ozden, 2009). If the participant verbally responded to the drawing, I was going to audio-record the conversation so I could reflect the participant’s descriptions. If a participant preferred not to draw, I had planned to offer a photo elicitation option of stock photos that represented various gender- presenting individuals and engaged the participant in questions around self-identification.

Ultimately, my participants were not interested in engaging in a self-portrait activity as described above. Kelly is a talented artist and I thought that incorporating a self-portrait activity would be an interesting way to privilege her talents and interests, but when I suggested it, she told me that she was not interested and doing it felt like an assignment. In Chapter V, I explain in more detail the way that the self-portrait activity evolved with Zula. She did ultimately do a

self-portrait, but we did not engage in the follow-up interview portion of the activity. Jordyn was not interested at all in doing a self-portrait. Art-making activities with Zula and Jordyn ended up being much more open-ended. By creating artwork together, I was able to learn more about Zula's and Jordyn's interests, their communication styles, their creativity, and their world views rather than a structured way to elicit specific information.

Another element that I had planned to engage in was a photo elicitation interview where I would use photographs from either a participant past school or stock photos representing schooling locations (locker room, classroom, outdoor recess area) and had planned to engage the participants in a conversation around these images (What do these images make you think about?) or a sorting activity (Where did you feel the most comfortable? Least comfortable?). Graphic and photo elicitation are particularly appropriate for individuals who used augmentative and alternative communication (AAC) supports to communicate. "AAC strategies frequently incorporate visual symbol, photographs, or images to scaffold and augment other communication modes" (Teachman & Gibson, 2018, p. 39).

Across all three of my participants, I incorporated aspects of photo elicitation. With Kelly, I created a slideshow of her elementary school building and found a YouTube video that showed the interior of her preschool. These images triggered various memories for Kelly and provided another way to explore memory in relation to space (What was your favorite space? Do you remember a space that felt safe/unsafe?) With Zula, websites of past schools and stock photographs did not interest her, but we did engage in several research discussions around comic books that featured scenes of schooling, specifically the Powerpuff Girls series. Working with Jordyn, we used old yearbooks as the main research activity. I photocopied old yearbooks of Jordyn's and she would engage in various collage-based activities of cutting out photographs of

students and past teachers and creating new collaged images. I cover in more detail the ways in which Jordyn preferred a more open-ended approach to engaging with the images rather than following the prescriptive photo-sort activity, as described above.

Visual methodologies also included in the research study included viewing TV shows, YouTube videos, and comic books. These popular culture productions were powerful ways to "examine pre-existing visual representations" (Pink, 2015, p. 37) and created a shared space to unpack and explore notions of gender schooling and memory. Multimedia ethnography examines new forms of digital media to better understand participants' meaning making (Dicks et al., 2006; Underberg & Zorn, 2013). When Kelly mentioned a favorite cartoon character, I ordered two copies of a comic book that featured the character from the cartoon, "Dexter's Laboratory" (1995). We read the book together and she shared various ways she remembered acting like a character and why she felt connected to this cartoon. It was an interesting way to reflect back on how she saw the world at that age. With Zula, pop culture references dominated many of our sessions including reading Powderpuff girl cartoons, drawing various cartoon characters, and watching episodes of SpongeBob SquarePants. These art-making experiences were a way that Zula both shared her schooling memories and a way she shared herself with me. In my sessions with Jordyn, she often referenced pop culture when she viewed various YouTube videos or music from YouTube on her phone during our research meetings. Because the research activities so heavily influenced the way that I understood each participant, I detail each of these approaches in greater detail in each participant chapter.

Semi-structured interviews. In designing this research, I wanted to forefront multimodal research approaches, however, for one of my participants Kelly, she referred a more traditional interview approach. It was important to be open to my participant's preferences. DS researcher

Mark Anthondy Castrodale (2018) aimed to do a "go-along" interview approach with undergraduates who identified as disabled. His plan was to position the participant as expert who would guide him through their lived space at the university. When Castrodale introduced the idea to participants, however, nearly all of his participants did not want to engage in the mobile interview and instead preferred to pick one familiar and static location (i.e., a café, the library). This "methodological flop" (p. 47) revealed many uninterrogated assumptions by the researcher: participants often noted they were concerned about heightened exposure to surveillance. Movement through the institution via mobile interviews was thus considered risky (p. 51). Although I had not planned on it, semi-structured verbal interviews were the preferred modality for one of my participants, Kelly.

In designing my interview style, I followed a narrative inquiry approach to interview questions is an open one so that "stories can be told" (Kim, 2106, p. 106). The goal is to have the participant feel comfortable and allow them the space to explore an idea or concept. Kim framed the interview process into two parts: the narrative phase and the conversation phase. In the narrative phase, the researcher asks open-ended questions and does not interrupt. I found Wengraf's (2011) "lightly structured" or "soft interview" approach helpful to frame the narrative phase. Wengraf advised that researchers ask a single question ("Can you tell me about _____?") and avoid asking questions for clarification. Fact-based clarification questions can derail the participant's narrative flow. Researchers should avoid interrupting the participant, take brief notes to remind themselves what to come back to, and engage in deep and active listening with the participant (Wengraf, 2011).

Oral historian Morrissey (1987) suggested a similar approach involving a statement and a question. I liked this style because it acknowledges the researcher/participant relationship and the

way that the narrative is being co-constructed (Kim, 2016). For example, after spending time with my participant and learning about Kelly's schooling history, I asked, "We've talked a lot about what school was like for you, especially your relationships with teachers. Can you tell me more about peer relationships?" Once a researcher engages a participant in an open-ended narrative interview, they then follow up with a more conversational interview approach where the participant and researcher are co-constructing a narrative together (Kim, 2016). In this dialogic interaction, the researcher asks the participant pointed questions to clarify meanings, events, and timelines (Goodson & Gill, 2011). This second round of interview questions is iterative and comes from the participant's original life narrative. Wengraf's (2011) soft interview and Morrissey's (1987) two-sentence format technique served as templates for my interview protocol, although flexibility and responsivity to my participants were important (see Appendix A).

Kvale (1996) suggested that a minimum of three rounds of interviews should be done for life storying projects. With Kelly, I conducted several (semi)-structured interviews, each not exceeding 60-90 minutes in order to be respectful of my participants' time and the potential for communication fatigue. I audio-recorded each interview, transcribing it fully before our next meeting to allow for a natural flow from one conversation to the next. This also gave me the opportunity to bring back past events and to allow Kelly to expand or connect various themes across different childhoods stories.

Additionally, I did one interview with the mother of each participant. Family interviews were purposely less frequent because they were not my key participants, although because I was working in Jordyn's home, I had more face time with Ada as compared with Kelly and Zula's mothers. Additional time outside of interviews—when I and a participant were sharing together,

working on a multimedia aspect of the project, or commuting to a location together—provided opportunities for "small stories" to occur. Kim (2016) explained that small stories are "narratives that are performed in everyday conversations" (p. 306) that can provide rich context for a participants' sense making. During interviews, I audio-recorded the conversations so that I could later transcribe the data and be more fully present in the moment of the interview. During my research meetings with Jordyn, I used videotaped recordings to capture nonverbal communication gestures.

Field notes and narrative memos. As a participant observer, I took detailed descriptive and reflective field notes (Bogdan & Biklen, 2007) and narrative memos (Clandidin & Rosiek, 2007). These reflective field notes included thick descriptions of my participants, including their words, actions, and behaviors as well as their larger social words (Geertz, 1973; Holloway, 1997; Ryle, 1949). Thick description understands that observation always involves interpretation, and the subjectivity of the researcher is never external (Geertz, 1973). I embedded artifacts into my field notes so that I could look at the data holistically rather than separate out image from text. Reflection is an essential aspect of a narrative inquiry project as the researcher and participant are co-constructors of the narrative: "The researcher should constantly take stock of their actions and their role in the research process and subject these to the same critical scrutiny as the rest of their data" (Mason, 1996, p. 6). Separating observations (descriptive descriptions of the events taking place) from reflections (what was coming up for me as the researcher) was helpful when I was making field notes (Emerson et al., 2011). An excerpt from my pilot study with June in presented in Appendix B.

Narrative memos, an adaptation or narrative turn on analytic memos (Charmaz, 2014), are spaces to engage in this reflexive process where the researcher can openly reflect on what

stories are coming up from their own lives. Memos also create a space for the researcher to begin to work out theory and is an initial space of analysis that can be represented in many forms, including letter writing, poems, art making, or journaling (Birks et al., 2008). In the spring of 2016, I took a course with Professor Kala Naraian on narrative inquiry. My project for the course was working with a teaching assistant to better understand her as a teacher. I used the narrative memo to work out some of the aspects of the research puzzle (Clandinin, 2013) and the ways I was framing her in a deficit lens. The memo was a space for personal exploration as well as a way to grapple with the research inquiry. I played with the data of a 30-minute classroom observation and flipped it from a deficit to a strengths-based perspective to "flirt with" (Kim, 2016) the ways I projected meaning onto this teacher's actions (see Appendix C for an example of a narrative memo).

I took detailed reflective memos before and after each of my research meetings with each participant. Oftentimes, I would use a voice memo option so that my ideas could flow freely. These memos were extremely important for my research process and created a space for me to work through the elements of co-construction with my participants. Reflective memos are an important tool in narrative inquiry and, as Clandinin and Connelly (2004) noted, "the inquiry space, and the ambiguity they implied, remind us to be aware of where we and are participants are placed at any particular moment—temporally, spatially, and in terms of the personal and the social" (p. 89). I was able to record my own reflexive process: What was I expecting? What materials did I bring today? What came up last time that perhaps we could revisit? How could I make my participant feel more at ease today? What was I feeling before going into the meeting?

Narrative memos are also a space to begin working though analysis and interpretation of the data, both thematically as well as theoretically. Intersectional theoretical frameworks of DS,

including queer theory, feminist theory, and CRT, were important constructs to pull from as I tried to make sense of the data. Narrative memos create a space to "flirt with" the data, making space to see the data in new and curious ways (Kim, 2016, p. 185). Maggie MacLure (2013) urged researchers to follow the "glows" of data, data that leave a researcher confused, curious, or wondering. I found this framing of data analysis to be incredibly generative because it acknowledged the relational space between the researcher, the data, and the participant, and it fit well with the relational stance of narrative inquiry. Often, I would be struck by a particular phrase that Kelly would use, a gesture that Jordyn would repeat, or an image that Zula would share with me. These stuck and lingered with me as I rode the subway, walked to work, or did the laundry.

Timeline

To approach this research from a narrative inquiry DS stance, I took my time to establish rapport and positive relationships with my participants. I established routines and norms for our researcher relationship. In what area could I help support my participant? How can the researcher relationship be mutually beneficial? What kinds of modes of expression does each participant feel comfortable with (verbal interview, drawing, on-the-go, multimedia)? Because this all requires time, I spent 6-8 months, approximately 3 times a week for 2-3 hours, collecting data and working with my participants. This amount of time allowed for a thick description (Geertz, 1973) of the lived experiences of my participants.

Validity, Reliability, and Trustworthiness

Validity has been a long-discussed concept in qualitative research. Traditional notions of validity come from a qualitative research stance that understands truth and untruth to be fixed and measurable (Cook & Campbell, 1979). Qualitative methodologies question objective notions

of truth as static. Instead, qualitative researchers use alternative framings of validity because "the language of positivist research is not congruent or adequate to qualitative work" (Lincoln & Guba, 1985, p. 95). To establish trustworthiness within the research, long periods of engagement should be established within the research context (Eisenhart & Howe, 1992; Lincoln & Guba, 1985). Triangulation of data sources is reached when there are multiple forms of data (Eisner, 1991; Lather, 1991), thick descriptive and reflective field notes (Geertz, 1973), and an open dialogue with participants regarding the research process (Clandinin, 2013). Reliability within data collection was maintained throughout the process by audio-recording and transcribing interviews, photo documentation and scanning of artifacts, and keeping thick descriptive field notes (Geertz, 1973). Videotaping was included in my research meetings with Jordyn to capture her nonverbal communication.

Throughout my analysis process, I collaborated with my participants by using member checks to ensure that I was privileging their meaning making (Clandinin, 2013; Creswell, 2007; Creswell & Miller, 2000). Implementation of member checks was negotiated and adapted once I recruited my participants in order to honor and privilege their preferred mode of expression. Member checks included participants collaborating with the researcher to confirm interview quotes for accuracy or adjust or correct narrative descriptions (Coffey & Atkinson, 1996; Doyle, 2007). In a project that privileges participant meaning making, member checking is a way to "ensure that participants' own meanings and perspectives are represented and not curtailed by the researcher's own agenda and knowledge" (Tong et al., 2007, p. 356).

Member checking looked different for each participant. Rather than wait until the end of the project to share a draft with the participant, I folded in member checks as part of my data collection and analysis process so that they were iterative and ongoing. Harvey (2015) described

a form of "member check interviewing," which involved sharing the first interview transcript with a participant and discussing the content of the first interview as a way to create the second interview collaboratively. With Kelly, I engaged in a version of this iterative process. Between each of our research meetings, I transcribed the entire interview and then highlighted several key questions or themes that emerged from the interview. Then in our following session, I would begin with something from the last interview. Often, I would read an excerpt from our interview as a way to begin the next research session. Engaging with Kelly during the coding process was not an option due to her work schedule. Because she was working on a healthcare app, her workload during the pandemic was extreme. Instead, I communicated with Kelly occasionally throughout the writing process. This involved a conversation where Kelly chose her pseudonym for the draft and also shared a Spotify playlist with me that I listened to during the data analysis and writing portions of her draft. I found this helped me to better privilege her sense making and have a more immersive sensory experience with her story. I shared a draft with her, and Kelly had a few minor revisions but overall felt that the draft had fairly represented our time together and told her story with efficacy.

With Zula, member checking occurred with both Zula and her mother Patricia throughout the research process. Between sessions, I would text Zula to confirm a preference she had communicated or to clarify a memory she had shared. Zula and Patricia chose her pseudonym. Zula gave me song suggestions that helped me to create a playlist I listened to while writing her chapter draft. Patricia was also very helpful throughout the process in clarifying details from Zula's school past. I shared a draft of the chapter with Patricia, and she was happy with the particular framing of Zula's school story. I read a draft of the chapter to Zula over Zoom and

asked her several times if she had any changes. She was happy with the chapter and said she most enjoyed seeing her artistic renderings throughout.

Jordyn's member-checking process involved an ongoing relationship with her mother Ada as well as Jordyn herself. I would check in with Ada at the beginning and end of each session to ask questions or clarify things. Throughout our research meetings, Jordyn communicated clear preferences around the activities she did and did not want to participate in, and I understood this as an element of member checking. For example, when I attempted to engage her in more traditional photo elicitation activities around specific spaces in the school or around particular faculty, she was not interested. Her preferences became the driving force of our time together. Due to the pandemic, I was not able to sit down with Jordyn to go over various drafts of her chapter. Jordyn does not like Zoom or Facetime. When writing the draft, I listened to Jordyn's preferred musicians—something I knew well from our time together—and returned again and again to her collages and photographs. Because neither Ada nor Jordyn had a preference for a pseudonym, I chose it myself. I communicated with Ada about questions throughout the writing process and also shared a draft with Ada which she, in turn, shared with Jordyn. Ada expressed that she was very happy with my particular telling of Jordyn's narrative and was appreciative that I was committed to "telling so many voices of young women on the spectrum." Ada described that Jordyn was eager to sit with Ada to review the draft and took particular interest in the collages and photographs.

Methods of Data Analysis

DS-informed narrative research comes from an emic perspective, aiming to highlight the ways of knowledge and stories from my participants. My data analysis therefore came from my participants' meaning making. Rather than come to the data with predetermined codes (etic

approach), I used a grounded theory approach to analysis (Glaser & Strauss, 1967; Strauss & Corbin, 1994). Grounded theory works from the ground up (Creswell, 2007; Tracey, 2012) and involves the researcher working with the data to discover themes and larger narratives. Data analysis was inductive and iterative, aimed at exploring the messiness of the data rather than creating neat and distinctive categories (Bogdan & Biklen, 2007). There were multiple rounds of data analysis, beginning with an open coding process (Glaser & Strauss, 1967; Strauss & Corbin, 1994). I recorded and transcribed interviews and then used descriptive in-vivo coding of pieces of the data (Miles et al., 2013).

I had some experience working in this approach over the course of the 2016 school year when I collaborated with Professor Naraian and another graduate student on the analysis and interpretation of qualitative data that Professor Naraian had previously collected. The research project was a narrative research study of a high school-aged young woman with disabilities and her use of assistive technologies. Throughout this process, Professor Naraian illustrated the importance of bucketing the data, selecting large chunks of data rather than small snippets or words, in order to hold the narrative integrity of participant meaning (Green, 2015). Once excerpts of interviews and field notes were collected into large thematic buckets, then a second round of analysis was used to parse out more specific themes or codes. Finally, a narrative was constructed from this iterative process. Connelly and Clandinin (1990) called these analytic tools *broadening, burrowing,* and *storying/restorying. Broadening* looks for connections to the larger context, including the literature review. *Burrowing* examines specifics of details and the feelings of participants (Kim, 2016). After the researcher engages in rounds of borrowing and bucketing, they work to s*torying/restorying* these themes within the specific narrative of a participant (Kim, 2016).

Each of my chapters required a slightly different approach to data analysis because the data collection process was individualized to each participant's preferences, interests, and communication styles. Kelly preferred verbal talk-based interviews. Over the course of 7 months, Kelly and I met seven times in person (prior to the pandemic) for a total of 8.5 hours, and we held our eighth and last meeting over Zoom, during which I interviewed her and her mother together. At the end of all of my meetings and interviews with Kelly and her mother, I had a total of 140 pages. I began reading and re-reading these transcripts to form thematic buckets across stories. In organizing Kelly's ideas, I took out repetitions for clarity and cleaned up sections of the transcript by removing filler words or other idiosyncrasies of verbal speech (umm, ahh, like, etc.) (Seidman, 2013). Transcription became a form of interpretation (Reissman, 2008), a first level of analysis.

I then engaged in a second round of analysis where I looked for larger thematic connections across buckets and engaged in the broadening, burrowing, and storying/restorying process (Connelly & Clandinin, 1990). As a narrative inquiry project, I understood these thematic connections to be co-constructed by myself and my participants; thus, coding and analysis are aspects of the research relationship, "the making of meaning and the production of knowledge are always in process- a becoming" (Ringrose & Renold, 2014, p. 77). Much of this second round of analysis emerged from writing and rewriting drafts of Kelly's narrative. While engaged in the writing process, I would often play a Spotify playlist that Kelly had shared with me as a way to access her meaning making from a different sensory experience. In working through her narrative, larger themes emerged that showed patterns across timelines, people, and events—for example, the theme of "autistic community and care webs." In writing Kelly's

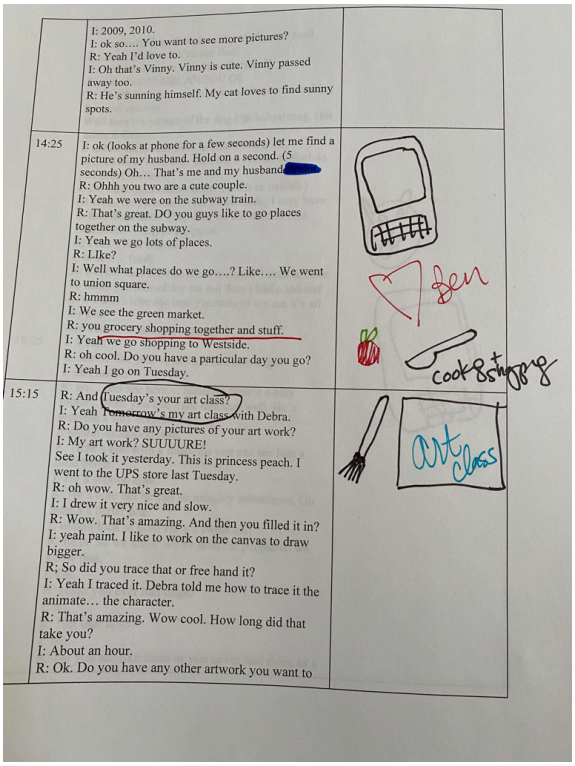
narrative, I used long quotes where Kelly described her own memories. Each section of Chapter IV was framed with a quote from Kelly as a way to forefront her own voice.

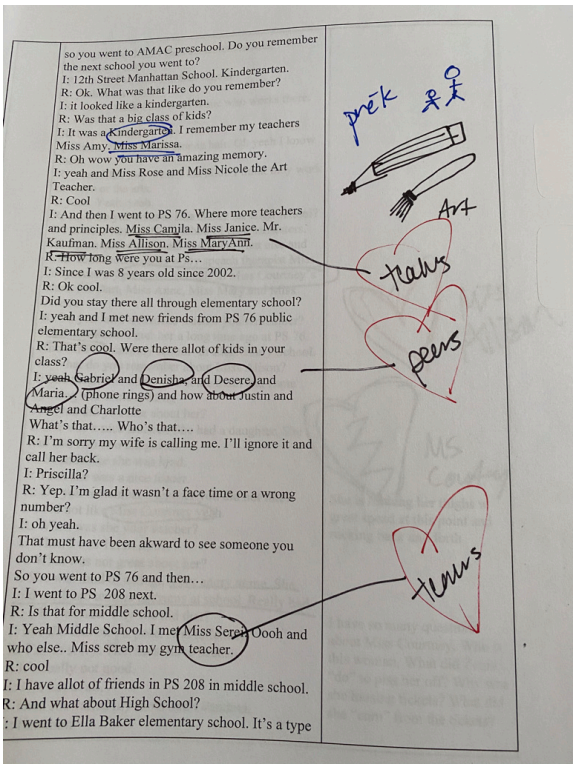
My meetings with Zula involved a much more multimodal research experience. We met 14 times over the course of 7 months for approximately 20 hours. I first approached the data analysis process in a similar way to how I had worked with Kelly. I began with a total of 133 pages of transcripts, reflective memos, and images. I began to bucket transcripts, but very quickly found that the process was not working. When I removed my own voice from the transcript, I realized I lost Zula's meaning making. More often, the conversations with Zula felt almost like a zipper, quickly shifting back and forth between us to create a tightly woven structure across both strands. The meanings in the conversation were produced relationally and isolating her voice from the context of our relationship made her sense making and speech patterns seem inauthentic. The work with Zula resisted a neat ordering of buckets and themes; instead, meaning making came from the interactions among people, objects, and body movements. During our Monday meetings, Zula shared her story in snippets—a drawing here, a text there, a significant silence, a familiar movement, an anecdote, a photograph. These snippets, woven together, represented a variety of life experiences. My role as interpreter was much more active with Zula than in my research with Kelly and, therefore, I included researcher vignettes as a way to reflect this co-construction process.

In working with the field notes, interview transcripts, pictures, and texts, I engaged in a tactile way with the field notes. I printed out all of the images and put them in a binder. I then drew, doodled, and colored in the margins of the transcripts and field notes, which helped me think about the data in a different way (Figure 8). Physically manipulating the transcripts helped me to see the connections. I assigned icons to think about various themes; for example, hearts

symbolized various kinds of relationships. I doodled in the margins using the colorful pens that Zula and I had used in our research meetings. In describing doodling as a form of analysis, Orellana (2020) reminded us that "materials matter" and shape our thinking to see patterns and relationships in new ways (p. 131). In doodling, I began to see larger themes including Zula's self-advocacy and the way she shared her perspectives in "text messaging." This approach also helped me keep the context of our conversations and interactions, something that was getting lost in the bucketing process. With Patricia's interview, I was able to use the bucketing approach as described above to find narrative themes regarding Zula's school story.

Figure 8. *Drawing as a Form of Analysis*





The above images in Figure 8 show two pages of interview transcripts from researching meetings with Zula. The left-hand side shows the time stamp from the recorded interview; the middle column is the transcription of the interview; and the right-hand column has room for

reflective notes or questions. I drew doodles and symbols as a way to think about larger themes across the interviews and field notes.

Working with Jordyn involved a multitude of different visual elements. Over the course of 6 months, I met with Jordyn 13 times for approximately 18 hours. During my meetings with Jordyn, I took photographs, audio recordings, video recordings, and field notes. I transcribed parts of the audio recordings after each session; however, most of our meetings together involved little verbal communication, and so reflective memos were very important to the research process. After each meeting, I would record a post-reflection voice to text memo. My memos included moments from my time with Jordyn and also parts of conversations with Ada. Ada was a big part of the research process and I engaged with Ada during each of my meetings with Jordyn. Some weeks, Ada and I spoke for 5 minutes; other times, we spoke for 30 minutes. I conducted a more structured interview with Ada halfway into the research study to learn more about Jordyn's specific school supports and diagnostic history. Ultimately, my work with Jordyn produced 63 pages of notes and transcripts, 57 images, and six videos.

In approaching Jordyn's narrative, I began with a bucketing process with Ada's contributions, both from our structured interviews as well as the small anecdotes she shared with me in passing or via text. These buckets included categories such as *diagnosis story, Jordyn's strengths and interests,* and *interventions*. I then engaged in a second round of analysis to look for larger themes across these buckets, which created the narrative structure of the chapter. For example, the theme "believers and non-believers" emerged from the second round of analysis and was a theme that stretched across multiple buckets (Connelly & Clandinin, 1990).

Engaging in data analysis and drafting Jordyn's narrative was an iterative process and involved several different approaches due to the varied nature of the participant and the data.

Many of the artifacts that Jordyn produced were picture collages from old yearbooks. Jordyn always kept the originals, a preference she made very clear. Between our meetings, I spent time examining the collages to look for connections between the photographs she selected and how she placed them on the page. I looked to literature about visual and arts-based methodologies and analysis to make sense of Jordyn's creations (Butler-Kisber, 2007; Pink, 2011; Rose, 2016).

At one point, I made multiple copies of Jordyn's collages and tried to engage in my own collage process to see what would emerge. I cut them up, reorganized them, drew on them to see if something new emerged in "flirting with the data" (Kim, 2016, p. 186). Overall, I did not feel good about approaching her collages this way. It felt disrespectful. In working with Zula's transcripts, I was able to maintain a sense of her original sense making and used drawing as a way to put various aspects of her story together in relation to each other. In approaching Jordyn's visual data in the same way, I was losing a sense of Jordyn's own sense making. As I layered on my own meaning, I was losing hers. I came to the conclusion that my quest to "unlock" some meaning in the selection and placement of particular pictures was an inherently problematic exercise. In attempting to map on meaning to these images, I projected my own specific schema of symbolic representation, a non-autistic schema (Biklen, 2005; Simplican, 2015). I inadvertently engaged in deficit framings of Jordyn, falling into a medical model trap of viewing her collaged images as a "puzzle to solve" (see discussion in Chapter I about the puzzle piece). I was pushing too hard with the data.

I began again, this time with no agenda other than to be more acquainted with the data, to remind me of what it felt like to share the space with Jordyn. I reread my reflective memos. I placed all of the collaged photographs on the floor to look at them together. I re-watched the short videos and audio recordings from our research meetings. I closed my eyes to hear the

subtle sounds from the space. I could hear Jordyn's voice, background music, my voice, the sound of scissors and glue as they were applied to paper, the sounds of Candyland pieces sliding on the gameboard. I watched the videos and then zoomed in on her hands as she created the collages. I then reexamined her collages while I listened to some of Jordyn's favorite songs. I started to write (on paper) what was coming up for me. I used the same pens that we used in our research meetings. This process helped me to "Slow it down. Step back. Sit with your data. Feel it. Listen more deeply" (Orellana, 2020, p. 128). Ultimately, this journaling process evolved into the vignettes that I share in Chapter IV and helped me understand larger themes in the work with Jordyn around communication and advocacy. I was then able to include her collages as a way to share her meaning making and her communication styles rather than as an *object* to examine.

Organization of Data

I collected a large amount of data for this project both because I incorporated multimodal approaches and spent a significant amount of time collaborating with my participants. Organization of my data was an important logistical necessity. I first organized my data by participant. All reflective field notes and narrative memos were dated and entered electronically and saved both by their chronological date as well as sorted by participant in electronic folders. All field notes and memos featured page numbers on them so I could create references. Early in the process, I created a table of contents for my data that included a log of my time with the participants and a summary of our activity. Dyson and Genishi (2005) discussed the importance of creating a system for data organization, "before artifacts retreat into corners of offices, the depths of tote bags, the odd pocket of this or that jacket" (p. 40). Any artifacts from the field or generated by participants (drawings, emails, a special object) were photographed and saved electronically, and each of these items was numbered. I followed Dyson and Genishi's model for

data documentation, replicating a version of their chart from *On the Case* (p. 40) but also adding a column for "artifacts."

Table 2. *Table of Contents*

Entry #	Date	Pages	Activities	Comment	Artifacts
1	3/2/98	1-4	Breakfast through activity time	Took few notes; tried to get a people, schedule, "lay of land" (map)	

Source: Dyson & Genishi, 2005, p. 40

Ethical Considerations and Researcher Positionality

As I entered this project to privilege autistic women's and girls' ways of knowing and their stories, it was important that I acknowledge my own identity as an outsider to the autistic community. I have been an educator working in schools for autistic youth for 14 years. I am a White, queer, able-bodied, allistic, cisgender woman. My participants are autistic women. However respectful and thoughtful I was and attempted to be, I was still in a position of power and authority as a researcher and doctoral student from Teachers College, Columbia University.

The role of able-bodied researchers has been long debated in the DS community. Simi Linton (1998) warned of the objectifying gaze of non-disabled researchers.

> The overwhelming majority of scholarship on disability either utilizes or implies the third person plural; "they" do this, "they" are like that, "they" need such and such. This contributes to the objectification of disabled people and contributes to their experiences of alienation. (p. 531)

A research design that privileges very specific and unique storying of three to four autistic women's schooling experiences aims to challenge notions of stock stories of disability and schooling experiences (Mitchell & Snyder, 2013).

I outlined my plan to engage ethically in the research process, including incorporating member checks, engaging in reflective field notes and memoing, and offering multimodal forms

of expression and interview techniques. Additionally, I developed a relational stance with my participants wherein I actively engaged in conversations including: Who was benefiting from this research? How can I be of service to this particular participant or to the autistic community at large? Dan Goodley (1999) outlined the tension for able-bodied researchers:

> Disability researchers walk a fine line between authentically capturing the actions of participants and reinterpreting those actions in [ableist] terms that emphasize victim images of disabled people. No researcher is infallible…. Disability research *with* participants can fall into research *on* participants—when the only person benefiting is the researcher and their career aspirations. However, critical reflections on subjectivity permit us to at least start unpicking the aims, directions, and finds of research and the researchers' role in this creation. (p. 43)

Without these interrogations, as an able-bodied researcher, I ran the risk of engaging in a medicalized gaze where I was the only one benefiting from the research.

Writing

I presented each of the participants' stories in their own chapter. Depending on the forms of data collected, I presented my findings with significant artifacts and visual elements to represent my participants' own perspectives. Kim (2016) referred to this as visual storytelling or a visual-based narrative inquiry. It was important to me that there be multiple ways to access the final document; therefore, incorporating images was a more inclusive access point that extended beyond simply reading the text. I used long blocks of direct quotations and participant art work to honor and privilege the voices and perspectives of my participants.

In each of my participant chapters, their mothers play an important role in telling their daughters' school stories. In Zula's and Jordyn's chapters, their mothers were the main narrators for their daughters' school narratives. Disability Studies understands the important role that parents play in sharing their children's stories (Adams, 2013; Alper, 2017; Berube, 1996; Ferguson, 2001; Kittay, 2019; Rapp & Ginsberg, 2011). These mothers are not speaking *for* their

adult daughters, but instead were speaking *with* their daughters because of the special and intimate role they have played as advocates and allies. The final project was a co-construction between my autistic participants, their mothers, and myself. I use vignettes in Chapters V and VI to make clear my own reflexive researcher position: "The final report provides for the voices of participants, a reflexivity of the researchers, a complex description and interpretation of the problem, and a study that adds to the literature or provides a call for action" (Creswell, 2007, p. 43). Ultimately, I want this project to both have scholarly significance and remain accessible to various community members. The aim was to not create a universal story, a stock story (Mitchell & Snyder, 2013) of autistic women's school experiences, but instead to allow for multiple ways to understand their schooling stories. Stories can tell multiple truths (Frank, 2010).

Challenges and Limitations

Quantitative researchers may view this study as limited in terms of its generalizability. They would argue that due to the small data size (three to four participants), there are real issues with generalizing the experiences of my participants to large populations, specifically other autistic women and their schooling experiences (Gerring & McDermott, 2007; Maxwell, 2004). Gomm et al. (2000) and Sharpe (1998) explained that this kind of statistical generalization can be referred to as empirical generalizability. Small sample qualitative research studies like this one are not aimed to address empirical generalizability nor are they aimed to "capture the universal" (Clandinin, 2006, p. 22) story of a particular phenomenon or community. In exploring the participants' stories, I did not aim to find an essential "truth" of autistic women's experiences, but instead sought to "reveal the multiple truths apparent in other's lives" (Emerson et al., 1995, p. 2). Narrative inquiry projects with small participant pools can have large-scale implications. For example, Clandinin (2006) pointed to the way in which Kitchen's (2005) narrative study of

one particular teacher's professional growth had large implications for the teaching profession at large. She explained the particularity of how Kitchen's writing and analysis allowed readers to "come to better understand the power of relationships in bringing about profound change" (p. 22). Rather than make a large statement about *all* autistic women, my hope is that this study will speak specifically to the individual experiences of several women. The particularity of this study is its power. What can be learned from these participants can have a big impact on schooling practices for autistic women and push to "imagine new possibilities" for future generations (Clandinin, 2013, p. 52).

FOREWORD TO CHAPTER IV

This is a distorted image of Kelly, a young White woman, who is drawing while sitting on the living room floor in her apartment. She has dyed pink hair and is balancing a sketchbook on her knees. The picture is a screen shot from an interview with Kelly and her mother that occurred on Zoom. It was also our last interview. The image is distorted due to internet connectivity disruption.

Figure 9. *Kelly*

Kelly and I first met on a busy, crowded city sidewalk on a beautiful crisp fall afternoon. I immediately recognized Kelly from her text description: “I’m a 28-year-old White woman, medium height, with dyed pink hair.” We headed to a bustling park near her job and sat at a wrought-iron table. I shared my goals for the research project: “I want to hear and learn more about the schooling experiences of autistic women. I want to think about how to prioritize each

individual's preferred communication style in the research." After I briefly explained my study, Kelly smiled broadly and said, "This should be fun. Autism is one of my special interests too."

During our initial meeting, I learned that Kelly was diagnosed with autism as an adult, first self-identifying at 18 and then later receiving her official diagnosis at 19. After receiving her diagnosis, Kelly was active in seeking out information about autism, both through first-person perspectives as well as autism research. In college, Kelly developed a large network of autistic friends and became a featured speaker at autism-related conferences. After college, she enjoyed working as a teacher and nanny for children with various disabilities before becoming a successful coder for a healthcare company.

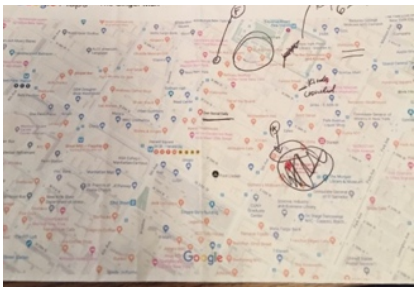
Throughout her school years, Kelly attended general education public schools; she did not receive any additional therapeutic support or accommodations. Although she did well academically, she struggled with peer relationships and was often in trouble with her teachers for what they viewed as disruptive behavior. Kelly's mom, Judy, played a key role in helping Kelly navigate these school dynamics. Kelly's parents divorced when she was young, and Kelly was primarily raised by Judy. Kelly and Judy's strong relationship greatly impacted Kelly's development. Judy and her close relationship with Kelly are a huge part of Kelly's narrative.

Setting the Scene: Finding a Research Rhythm

In beginning the research together, my initial concern was location. I wanted our meetings to feel easy for Kelly. Kelly works 40+ hours at her job as a coder. I needed to find a location close to her work, with comforting food and drink options, quiet enough to record and hear our conversation, and without a rushed vibe so we could sit undisturbed for long stretches of time. This proved to be a difficult task. After our initial meeting in the park, which was noisy and distracting, I spent the next week walking her work neighborhood and searching for a suitable

spot. I thought a lot about the physical experience of the research. I thought about things like background noise and the types of lighting available, and I questioned: Is there a florescent hum? Is there a clean bathroom? Are the tables shared or are there small tables where we can sit privately? Are there stools or chairs? What music is playing in the background? Is there table service or counter service? All of these factors would impact how long we would feel comfortable staying and the kinds of stories she would feel comfortable sharing. I took a full week to find the right location, ultimately walking a five-block radius and taking location notes on a map I kept in my field notebook.

Figure 10. *A Small Picture of the Printed-out Google Map*



This image is purposely small to obscure the actual location of the Google map I used to record notes on the various locations I scouted when picking a meet-up location. The map shows various cross streets and scribbled handwritten notes.

I finally found a café that proved to be our regular spot, just two blocks from Kelly's office. The café possessed a French patisserie feel with soothing lights, generic yet not distracting jazz music (think Ella Fitzgerald covers), pastries, hot tea, private tables with chairs—not stools, counter service, and a clean bathroom that did not require a key for entry. We met at this location five times: each time, I arrived early to secure the same corner table. After carefully wiping off any crumbs on the table, I headed to the counter to order two large mint teas and

sometimes a treat, like a small collection of madeleine pastries to share. It felt important to make the space feel inviting and comfortable, a place where Kelly wanted to stay. I also wanted to reduce the extra labor of negotiating meeting specifics, the back-and-forth texts…"Where should we meet? What time? I'm here? What do you want me to order?..." I wanted an established routine for our meetings; out of routine grow comfort and intimacy. Each of our meetings lasted anywhere from 1 to 2 hours. It was common for us to lose track of time. Often, our meetings ended with a chime on her phone, a reminder Kelly had set for herself to pick something up on her way home from work: "buy dry shampoo." The chime interrupted the temporal space of storytelling and alerted us both to the present moment: "Oh gosh it's getting late. I didn't realize how late it is. I should go." On two occasions, we stayed until the café closed.

Over the course of 7 months, Kelly and I met seven times in person (prior to the pandemic) for a total of 8.5 hours and held our eighth and last meeting over Zoom, during which I interviewed her and her mother together. Before the pandemic, Kelly and I occasionally cancelled our in-person meetings; I was transparent with her about my reasons for cancelling because I wanted cancellations to feel normal. I wanted her to feel that meeting was not a requirement. During our second meeting, I discussed the power dynamics of researcher and participant and expressed my goal that she should feel empowered to stop the process at any time should she feel uncomfortable or overburdened. She thanked me for bringing up the conversation and assured me that she was "Good about setting up boundaries" and would be clear about any reservations as they arose.

Chapter IV: KELLY

"This should be fun. Autism is one of my special interests too."

Kelly is a gifted storyteller; our conversations flowed easily and our comfort with one another grew quickly. Kelly has a talent for expertly weaving together her memories, knowledge of the larger field of autism and autism research, and the neurodiverse experiences of her vast network of autistic friends and colleagues. I was immediately struck by her knowledge, the clarity of her memories, and her self-awareness: "I have a really strong memory and can remember things from when I was really little. I remember things from a visual and sensory experience." Often, a story was peppered with specific details—the color of a favorite toy, the physical facial features of an unfriendly teacher, or the type of chair in her elementary school library. Her stories were rooted in sense memory and, as she shared each story, I saw her almost get transported back to that moment in time. Many of Kelly's memories focused on preschool, kindergarten, and early elementary school; therefore, her early life dominates much of her story. In storying and restorying (Connelly & Clandinin, 1990) Kelly's narrative one of the strongest themes from Kelly's story was the role of relationships and the ways that Kelly was read within these relationships.

Finding Herself Through "Care Webs"

"I wanted to know why I was acting the way I was"

Disability activist and scholar Piepzna-Samarasinha (2018) described "care webs" as networks of disabled community members and non-disabled allies who collaboratively work to support one another's needs. These disability communities become sites of organization, connection, and collective wisdom. It is within these communities that one learns about one's disability identity, ways to navigate the world, and what supports to seek out. Kelly had several

different care webs in her journey towards self-diagnosing as autistic at 18 and later receiving an official clinical autism diagnosis at 19. These communities started online and then evolved into autistic friendships in person. Kelly's mother was a key supporter and advocate for Kelly as she navigated the clinical diagnostic process. Though these various support webs, Kelly was able to claim a name that matched her lived experience: autistic woman.

Autistic Community

Kelly spent her teen years searching for answers. She wanted to name how she felt and how she experienced the world: "I wanted to figure out what was going on with me. What was wrong with me? Why I was acting and feeling this way?" She went looking for answers online. At first, she found girls who blogged about their mental health experiences on LiveJournal, a kind of precursor to Facebook that was popular in the early 2000s. The platform allowed for individuals to post pictures and blog entries, and to communicate via comments on each other's posts. LiveJournal became a place where people found community. Kelly connected with teen girls from all over the world who shared experiences with Bipolar disorder, ADHD, and depression. It was empowering for Kelly to connect intimately with such a huge network of women and girls who were able to share their similar experiences of the world. Forming meaningful online friendships is a common experience for autistics as they search for commonality and connection (Elcheson & Lesko, 2018).

Through LiveJournal, Kelly was introduced to Wrongplanet, a website where autistics blog and share their personal experiences. Kelly experienced an immediate sense of connection with the other site users. As a teen, she was diagnosed with ADHD but never felt that the diagnosis fully captured her experiences. She was, however, particularly drawn to the experiences of autistic women online: "Reading all of the thousands of backlogs and what people

were like beyond the DSM criteria and I was like ooohhh, this is like what's up with me." Having access to online communities of other women and girls with a similar experience was essential for Kelly's own self-discovery. Through the message boards and blog posts, she started to feel a strong sense of belonging, something that would have been difficult to find in real life where Kelly did not know any autistic women or girls.

Kelly's first big in-person connection to autistic community started with a friend-turned-boyfriend, Cameron. Cameron and Kelly met in high school through her first boyfriend, Chris. The three of them often hung out together. After meeting Cameron, Kelly felt a strong sense of connection.

> I started feeling that me and Cameron were the same person. I had this feeling that we were soulmates. We were so similar in the way that we saw the world and the way we would talk and our body language. Now in hindsight, I realize we weren't similar. The things we had in common were autism symptoms.

This immediate intimacy and ease with Cameron presented a stark contrast to her then-boyfriend, Chris. When Kelly met Cameron, she felt they immediately understood one another; she felt a sense of ease and did not feel the pressure to be anyone different than herself. However, with her boyfriend Chris, who Kelly described as a "caricature of neurotypicality," she always felt under the microscope. Chris took on a teacher role with Kelly, frequently correcting her and explaining why she should behave differently. "If there is logic on one side and emotion on the other, Chris is allllll the way on the side of emotion." Kelly described Chris as always trying to "fix me as a pet project," pushing her to become more emotional or respond differently in social situations.

At first, Kelly welcomed his insights into the way others perceived her socially. After years of confusing social interactions, here was Chris, ready to explain where Kelly was going wrong socially: "I wanted to know why I was acting the way I was." Kelly told the story of

meeting Chris's mother for the first time. When she asked Kelly, "How are you?" Kelly smiled and said, "Fine." Later that evening, Chris asked Kelly why she was so rude to his mother: "Why didn't you ask her how she was doing?" Chris explained social nuances in concrete ways that Kelly found helpful.

> Of all the neurotypical people, Chris was the best at consciously understanding and being able to articulate emotional or abstract niceties and the reasoning behind them. So, after he confronted me about his mom, I started practicing that and asking how someone was, even if I didn't care and they didn't care. I started seeing it as recognizing and acknowledging that both people are equal humans with an equal experience and it's a tiny blip to demonstrating care. It makes people feel that you like them. And if you demonstrate that you like someone, they will like you in return.

The feeling of support and helpfulness soon faded as Kelly felt increasingly misunderstood and judged by Chris, "I learned so much from him. I think sixty percent of the social skills I learned from him. But him being a teacher ALL of the time…. It was not a healthy dynamic." As her relationship with Chris waned, Kelly and Cameron became closer, eventually dating at the end of her senior year of high school.

After years of feeling isolated from others, Kelly found an autistic community through Cameron. Cameron was part of a large autistic network and was a paid speaker on autism advocacy panels and conferences. Additionally, Cameron's father, Kevin, is an autistic writer who wrote a popular autobiography. Kelly described Kevin as "autism royalty." As Kelly pursued a professional autism diagnosis, she found Kevin's biography confusing. Instead of seeing herself reflected in his writing, she felt estranged from his experience: "I remember reading Kevin's book and thinking maybe I'm not autistic because I'm nothing like Kevin." This realization led her to start reading more specifically about autistic women and girls, and she began to see the ways in which her experience as an autistic girl, and now woman, was different from her boyfriend's experience and those of her other male autistic friends.

Judy as Ally

Gaining access to autistic communities increased Kelly's sense of her autistic identity and her desire to pursue an official diagnosis. Kelly, however, was not sure how her mom, her biggest supporter, would react when she told her, "Mom I think I'm autistic." She worried that Judy would not understand: "I thought my mom would say there's nothing wrong with you. I was an early talker and was a little professor type. I got good grades." Kelly often described the special connection she shared with her mom: "My mother really was the only one who understood me." When most adults became frustrated and tried to control or discipline Kelly, Judy worked to explain ideas in a way that made sense to Kelly. For example, one of Kelly's earliest memories was of Judy patiently explaining the reason why Kelly had to sit in a car seat—a conversation that took place daily because Kelly hated the car seat. She felt restricted and disrespected by having to ride in the backseat. Instead of forcing her, Judy explained over and over again why the car seat was important.

> She [Judy] was the only one who took the time to logically explain why I had to get in the car seat. I always wanted to jump around in the back of the car and touch everything. The car seat was too tight and restricting. I felt like a second-class citizen sitting in the back of the car. My mom would spend ten minutes explaining it to me that if I wasn't in a car seat, she could go to jail. The car could crash, and I would get hurt. She would logic through the entire reasoning behind why it was necessary. No one else had the patience to do that.

While other adults, like her grandmother and, later in life, Kelly's teachers, assumed that Kelly was defiant, Judy believed her daughter had good reasons for her "defiant" behavior. Rather than using discipline or threats, Judy worked hard to explain clearly the consequences of Kelly's choices. The goal for Judy was not compliance but understanding. Judy knew that when things were explicitly spelled out for Kelly in a way that made sense to her, she was much more willing

to comply with a request. Kelly was hopeful that Judy would once again understand her perspective and help support her through the clinical diagnostic process.

Kelly gave Kevin's autobiography to Judy as a way to help her understand a broader range of autistic expressions. Kevin was an accomplished writer and speaker, someone who had excelled in school; Kelly wanted her mother to understand that autistic people could excel academically but also struggle with social connections, anxiety, and sensory overload. After finishing Kevin's memoir, Judy surprised Kelly by saying, "Well, I always thought your dad was textbook autistic." Kevin's memoir helped Judy see the connections to her ex-husband and, from there, to Kelly. Judy quickly got on board and together they researched next steps for the clinical diagnostic process.

One of the reasons Kelly felt she and her mother are close is that Kelly believes Judy is also autistic. She told me "My mom is autistic too" several times throughout our conversations. Kelly described her mother as "performing" when engaging in group conversations and small talk: "She'll sit quietly and tap her foot and contribute very little to a group conversation but will add an 'Oh yes' or 'Fine' to the conversation as a kind of script." Judy, however, will completely transform when the topic of conversation shifts to her interests.

> She has special interests like DIY home projects and when she talks about these topics, she'll immediately become animated and starts gesticulating and goes on and on about her deck project. She'll get so relaxed and animated. She can't be engaged unless it's one of her narrow interests.

When the conversation goes back to a general topic, Kelly described Judy as returning to a placid state with her hands in her lap, a bland smile on her face, and a "customer service" tone of voice. I never asked Judy explicitly if she identified as autistic, but I did ask if she shared a special kind of kinship with Kelly, if she and Kelly were similar as children, and if that provided Judy with a special perspective on her daughter. Judy answered that she and Kelly were very different as

kids. Unlike Kelly, who was often viewed as rebellious by her teachers, Judy was an exceedingly well-behaved child. In fact, her own mother often worried about Judy being "too compliant" and expressed concern that she would follow authority without question.

Despite the differences between mother and daughter, Judy has always had a keen ability to understand Kelly's perspective and to think creatively of ways to support and respond to her daughter. After Kelly asked for Judy's help in navigating the clinical diagnostic process, Judy did what she had always done—she supported her daughter. Judy quickly and thoroughly prepared for the diagnostic appointment by researching autistic women and Asperger's. Mother and daughter had already navigated a similar process during Kelly's teen years when Kelly received a diagnosis of ADHD—a diagnosis that Kelly described in the following way: "ADHD was what people who were autistic but talked and were female got in the 2000s." It was common for girls to receive an autism diagnosis much later than their male peers, after being misdiagnosed (Begeer et al., 2013; Giarelli et al., 2010). Going into the process, both Judy and Kelly felt worried that the clinician would not take Kelly's concerns seriously because of her verbal abilities and academic achievements.

Diagnosis

Kelly had a nuanced understanding of the role that gender expectations play in receiving an autism diagnosis because of her own experience, her extensive connection to autistic communities, and the significant amount of reading she has done on the subject. Clinicians who diagnose children with autism often look for classic manifestations such as an interest in mechanical objects or computers (Hendrickx, 2015). Kelly described the male expression of autism as classically interested in "planes, trains, and automobiles." She observed, "Autistic girls are not exposed to the same thing as autistic boys." Rather than an interest in transportation,

Kelly described that she learned from her peers, as well as from researchers who specifically looked at autistic girls, that autistic girls tend to pursue more gender-conforming interests such as animal facts, boy bands, fantasy novels, and make-up collections. Just like their male counterparts who have what Kelly described as "narrow interests," autistic girls may also develop specific interests and expertise in one particular subject. Those interests are camouflaged as typical girl interests, like Kelly's interests in art and animals (Dworzynski et al., 2012; Hiller et al., 2016). Kelly explained that because autistic girls often blend in more easily than autistic boys, they do not receive the support they need to navigate social dynamics.

Armed with information about autism in girls and women, Kelly and her mother attended her clinical diagnostic appointment together. She was 19 at the time and nearing her graduation from high school. Due to Judy's job as an administrator at a university, Judy and Kelly had access to an evaluation through their health insurance, a process that would have been extremely difficult to access without insurance. Judy was hugely supportive throughout the assessment; when the doctor asked for examples of autistic behavior from Kelly's childhood, Judy was ready with many stories. She described the way that Kelly was different from all of the girls her age: "She was hyperactive, but it was also way more than that." For over 30 minutes, Kelly and Judy talked with the doctor about Kelly's various sensory sensitivities and preferences, and the way she behaved as a child. Kelly described the years of exclusion she endured and her difficulty in coping with various sensory experiences. The entire appointment lasted several hours; Kelly completed many assessments and questionnaires with various professionals. She received her diagnosis after this first appointment. "When I read the assessment from the clinician, it basically said that I appeared obviously autistic when I first walked in the room." It was a huge relief to receive an official diagnosis because it gave Kelly more access to support needs such as therapy.

Receiving an official diagnosis gave legitimacy to Kelly's lifelong experience of feeling "different."

Because of all of the research that Kelly had done regarding autistic people's experiences, Kelly was able to situate the diagnosis of her experience critically within the contexts of time, privilege, race, class, and gender. Kelly was keenly aware that her clinical experience was easier than many of her peers. She understood that she was in a unique position to receive the proper diagnosis and recognized that even if she were a young child now, given all of the advancements in the field, her academic and verbal abilities would still likely be hindrances to receiving a proper diagnosis.

> Even now it would have been hard for me to get a diagnosis because I talked. It would have taken exactly the right person asking my mom exactly the right questions. Even the boys I knew that were my age didn't get a diagnosis until the late Nineties when they were like twelve or thirteen years old, and then only high-income people who were seeing specialist[s] because their kid was weird, and they wanted to do something about it. It's usually upper-class White people who get a diagnosis because they are exposed to the people who would know what specialists can give that diagnosis.

As a White woman with access to evaluations through her health insurance, Kelly keenly pointed out the racial and economic barriers involved in receiving a diagnosis and thus receiving necessary supports and accommodations. Black and Latino children receive a diagnosis on average 18-24 years after their White peers (Christensen et al., 2012). Additionally, Kelly's academic and verbal abilities allowed her to "pass" as non-autistic or neurotypical, which obscured the ways she struggled in other areas (Cook et al., 2018). External behaviors such as "hyperactivity" and "disorganization" got her a diagnosis of ADHD and medication, yet none of Kelly's underlying challenges socially or with her sensory system were addressed.

Receiving a diagnosis at the age of 19, as Kelly entered college, was an important step towards a better understanding of her own social and academic needs. Before receiving an ASD

diagnosis, Judy described Kelly as resistant to help, but after being diagnosed, Kelly was more open to receiving help for organizational support with her assignments and academic schedule. Judy also helped Kelly find a therapist who specialized in autistic women and mental health. Kelly described the therapist as "amazing" because, with her decades of experience, she helped Kelly contextualize her experiences in the broader lived experiences of other autistic women. Finally, with an accurate diagnosis, Kelly stopped judging herself for her struggle to stay organized with due dates and big picture tasks; receiving help felt supportive rather than judgmental and, finally, she had more answers to the original question that followed her through her teen years: "Why am I acting this way?"

Teacher Perceptions of Kelly: Stock Stories and Flexible Framings

"Teachers hated me as a child"

During Kelly's early school years, most of her teachers struggled to understand her, adopting a deficit and rigid perspective of Kelly. Disregarding positives like her early strengths in literacy, her teachers became fixated on the belief that Kelly's classroom behavior was intentionally disruptive. Kelly felt rejected by her teachers: "Teachers hated me as a child. I got kicked out a lot." Kelly as the problem became her stock story, the story that was reproduced repeatedly throughout her educational journey (Mitchell & Snyder, 2013). Two teachers broke the stock story. They each took a capacity-oriented and flexible approach towards Kelly and reframed challenging situations by embracing Kelly's interests and abilities. In so doing, they allowed for her strengths to emerge and broke the static stock story of Kelly as a problem (Mitchell & Snyder, 2013).

Kelly attended the preschool program attached to the university where Judy worked as a program administrator. In preschool, Kelly was inquisitive, talkative, and hyperactive. She

frequently interrupted to ask questions and showed early signs of sensory sensitivities. She was stimulated by loud noises and craved continuous movement. She often found herself standing during morning meeting, a time when all children were expected to sit. Kelly relied on physical movement to pay attention in class, but her physical activity challenged the expectations for classroom behavior. On a daily basis, teachers placed Kelly in time-outs. She was removed from the classroom or asked to sit away from the group as a form of punishment. Her teachers viewed hyperactive behavior as attention seeking and believed they needed to respond with firm consequences. In reality, Kelly was seeking movement as a way to regulate herself in a busy classroom environment.

Tactile input and movement were the ways that Kelly processed and made sense of her classroom environment and therefore were not behaviors she was capable of easily stopping. While Kelly was difficult to manage in the classroom, she also displayed gifts in reading and language acquisition. But these talents seemed to make Kelly even more of a target for her teachers. The combination of strong reading and language skills mixed with low impulse control gave her teachers the impression that Kelly simply was not trying: “I was treated like I was always falling short of everyone’s expectations, and not only always falling short but also that I was intentionally misbehaving and showing off.” Her strengths were weaponized against her.

Judy was frustrated by the daily preschool reports of Kelly’s “misbehaviors” and frequent time-outs. During this time, Judy and Kelly lived with Judy’s parents. Judy’s mother (Kelly’s grandmother) was constantly exasperated by her granddaughter and often complained to Judy about her lack of discipline. Consequently, Kelly’s deficit framing was reinforced by family as well as school staff.

> I talked with her teacher and I said, "I don't think that's [time-outs] doing what you're wanting it to do. You see it's never changed her behavior." And the teacher said, "No, she knows exactly what she's doing." And I told her, "I don't think she does. Her mind doesn't work that way." And so, she thought [the teacher] that Kelly was being intentionally misbehaving. And my mother [Kelly's grandmother] would oftentimes think she was intentionally misbehaving too. And that's why I felt like it was an adult issue. It wasn't Kelly's issue. It was the adults that were the problem.

Throughout preschool, Kelly was consistently seen as a problem by her teachers; Judy believed the teachers were the problem.

One of the "problematic behaviors" identified by Kelly's head preschool teacher was Kelly's refusal to flush the toilet. Kelly was afraid of the flushing sound, an early sign of her sensory sensitivities, but the head teacher saw her refusal to flush the toilet as willful defiance. This teacher, an older woman with years of experience, believed Kelly simply needed to get over her fear. Kelly described the teacher's approach: "The teacher's strategy was to say shut up, stop, and do this because I said so, and she would take my hand and force me to flush it. I thought they were all so mean."

Thankfully, an assistant teacher in the classroom took a flexible and capacity-oriented approach with Kelly. Since Kelly's preschool was part of a university, a number of the teaching assistants were young college students. The assistant teacher took a more playful approach with Kelly; "they actually liked little kids" she explained. Rather than engage in a power struggle over flushing the toilet, the assistant teacher incorporated Kelly's passions and interests to get her on board with the request. At that time, Kelly was deeply interested in birds. She often pretended to be a bird and would cleverly use this interest as a reason why she could not flush the loud toilet; "I can't do it because I have wings," she told her teachers. The assistant teacher capitalized on these interests in her approach to Kelly.

> I remember the assistant teacher telling me that if I was a bird, I could flush the toilet with my foot. I still do that now. Because they're really loud, she taught me to do the

> ocean noise thing like plug my ears and unplug them really quickly to make the sound of the ocean in your ears to block the noise. I still do that now because they are really loud. She gave me a lifelong skill.

Rather than challenge her reality, the assistant teacher accepted it and collaborated with Kelly. The teacher capitalized on her interests and incorporated them into the curricular goal, a strategy that DSE scholar Paula Kluth (2010) named as an important aspect of inclusive practice. Kelly accomplished the end goal, flushing the toilet, but did so through adapted means—with her foot. The teacher's flexibility allowed for multiple pathways towards success rather than one pathway, held in place by rigid expectations of normative student behavior.

Unfortunately, this flexible orientation was not shared by the majority of Kelly's teachers. Judy identified this inflexibility as the problem with which most of Kelly's teachers struggled; rather than invest time in explaining ideas to Kelly and learning more about her perspective, the teachers focused on controlling Kelly. Judy's approach was to think creatively and, like the preschool assistant teacher, incorporate Kelly's interests into home routines. When concepts were explained to Kelly in a way she understood, she became willing to go along with what was asked of her.

> It was all carrots with Kelly. That's what worked. When she was four, she went through a bird phase and I had to just go with it rather than try to fight it. I'd say, "Ok, put your wing into your coat," and she'd do it no problem. You had to put things in context so that they related to her rather than just her doing what she's told. Pushing her to do something just made it worse.

Power struggles between Kelly and the head preschool teacher escalated to a physical altercation that left Kelly with a dislocated elbow. The incident occurred when this teacher became frustrated with the length of time Kelly took to eat her yogurt at snack.

> To end snack, the teacher would ring a bell, but I would never be done. One day she got so frustrated with me that she got into a tug of war with my yogurt and ended up dislocating my arm.

Kelly spent the day "whining and complaining" about her arm with little to no response from the teacher. When her mother arrived to pick her up, she took her to the doctor who confirmed that it was dislocated. To Kelly's knowledge, there was no disciplinary response to her teacher's violence. For Kelly, this act of violence did not stand out as different from other school memories; the cruelty was commonplace, almost expected.

Kelly's kindergarten teacher took a very different approach to Kelly than her head preschool teacher. Rather than focusing on control, this teacher allowed Kelly to express herself and move freely in the classroom. Judy described Kelly's kindergarten teacher as one of her best teachers who used her 30 years of experience to support Kelly. This teacher paid close attention. For example, although this teacher noticed that Kelly "never looked at her in the eye or made eye contact," she remained unconcerned, confident that Kelly was listening in her own way. Judy recalled the teacher explaining that during lessons, Kelly often fidgeted, laid on her desk, or wiggled her fingers at her eye line instead of sitting upright and making clear eye contact with the teacher. But when asked questions about the lesson, "she [Kelly] could repeat it word for word so the teacher knew she was listening."

Kelly described her kindergarten teacher as her favorite teacher out of her entire school experience.

> My best teacher was my kindergarten teacher because she didn't really care what I did. Like if I was in a group, I would often put my head down, put my head on my knees, look down or away or rock back and forth (demonstrates it). My teacher didn't really care because she would ask me what she was talking about and I would repeat it. I was listening so she didn't really care if I was seated like eyes forward, hands quiet, sitting up (demonstrates it). She didn't care how "paying attention looked." The rest of my teachers really hated that and would constantly comment on that. The more they made a deal about it, the worse it got. Then I would get up from my chair. Then the other kids would get up from their chair. It was like a big deal. The kindergarten teacher was maybe my best teacher because she didn't get me in trouble.

Kelly used movement to regulate herself, to soothe her nervous system. When teachers attempted to shut down one of Kelly's self-soothing techniques, Kelly was forced to move onto another strategy that was often viewed as even more disruptive (getting out of her chair). In contrast, Kelly's kindergarten teacher allowed Kelly to move her body in the ways that felt natural to her. In doing so, the teacher gave Kelly the freedom to seek the input she needed to be present in the classroom. DSE scholar Kasa-Hendrickson (2005) explained that successful inclusive teachers have more expansive definitions of participation and understand rocking or flapping as forms of expression. Ironically, the less the teacher tried to control Kelly's movements, the less intense Kelly's need for movement became. Simply leaving Kelly to regulate herself was the least disruptive solution and led to Kelly's highest level of attention to classroom instruction.

Kelly's need to move was a constant issue throughout her childhood. Judy believed Kelly was judged through a lens of gendered expectations of appropriate behavior. When Kelly was 6 years old, she began gymnastics. The first year, gymnastics was a mixed-sex group and Kelly loved the classes. The next year, the group split up by sex, forming girls' and boys' groups, and Kelly's experience quickly deteriorated. The expectations for each group were completely different. The girls were supposed to wait in line and, one by one, perform a skill. The boys, meanwhile, were constantly moving and rough-housing. Judy described Kelly as "very different from other little girls. She was highly energetic. Here's Kelly acting like the little boys and she's

not doing what all the little girls do." The gymnastics instructor repeatedly asked Judy to reprimand Kelly and prepare her for the expectations of the class. From Judy's perspective, Kelly was not the problem: "All you have to do is move her from the girls' group to the boys' group. And she'll be fine." Kelly recalled that like gymnastics, any sex-segregated group was a problem for her as a child; she struggled to conform to gendered expectations of behavior. Kelly shared that many autistics struggle with these expectations,

> I don't think I know any autistic girls who are under the age of twenty, right now, who aren't trans or gender queer to some extent. I think it's because of this. I think that if that had been a concept when I was little, I would have ended up one of those like trans autistic teenagers. The expectations for little girls are so much more rigid that there's no wiggle room. It meant that if the adult was treating the group of kids like they were girls not kids, I was always doing something wrong. I did better in mixed-sex environments, because usually the expectation wasn't quite the same. Or in situations where it was mostly a boy thing because then the other kids, who were boys, were acting more like me. Adults don't have the same rigid expectations of boys. Boys are allowed to be quiet or loud or sitting still or jumping around, but girls are only allowed one of those choices.

Research supports Kelly's observation that there is a higher percentage of gender non-conforming and/or transgender autistics as compared to the non-autistic population (Van Der Miesen, Ann, Hurley, & De Vries, 2016). Rather than interpreting Kelly's movement as learning, exploring, or a way to cope with a busy environment, Kelly's movements meant she was a girl out of control.

Kelly's second grade teacher and guidance counselor also described Kelly's behavior as "hyperactive" and out of control. Judy reported that this counselor observed Kelly in the lunchroom and commented to her, "She never sat down. She never stopped talking. She never stops. She just keeps going. She was never under control." The cafeteria with the bright lights and hundreds of kids talking and moving was a particularly difficult space for Kelly's sensory system. She often became extremely overwhelmed and found herself removed from the lunchroom by the cafeteria aides when she became too active.

> I didn't conscientiously know that I had sensory problems until I was an adult, but in hindsight, that was one of the reasons that I was really hyper all the time. Because acting like that, I would often be removed from the situation. So, it would just get really crazy.

Not having the tools to know how to regulate herself in overwhelming environments, Kelly reacted and attempted to flee. Once again, her teachers interpreted her reactions as intentional defiance.

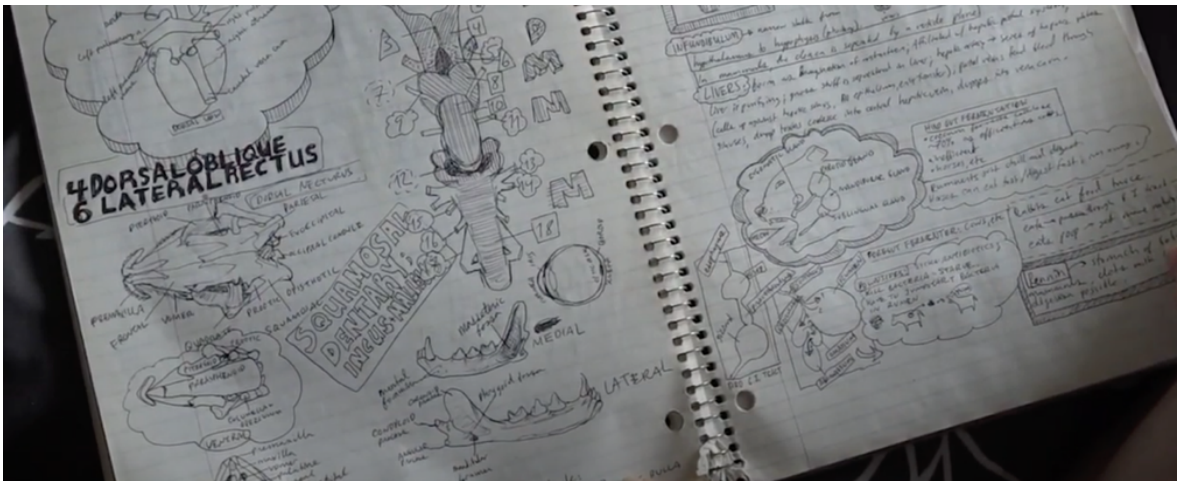
Kelly's second grade teacher started the year with a strength-based approach, but unfortunately, this approach was short-lived. Judy recalled that in September, the teacher described Kelly as a "philosopher with deep thoughts." By February, he described Kelly as the root of any classroom disruption: "So, if there's sand in the works anywhere, it's always Kelly. Whatever's going on, it's always Kelly's fault." The teacher used a token system of red tickets and green tickets; too many red tickets (for poor behavior like getting out of her chair) meant that Kelly stayed indoors for recess. The system resulted in Kelly rarely having recess with her peers and instead staying inside where she would chat with the teacher. Judy described the teacher as completely ineffective in supporting Kelly: "He said he wasn't really quite sure that was the right thing because they both seemed to enjoy the time so much. He wasn't sure that she was learning to change her behavior." Kelly struggled to meet her teacher's expectations because she did not understand them. She was able to follow rules that made sense to her, but no teacher was ever able to contextualize classroom rules enough to explain sufficiently the "why" behind them.

> I've always been very good at logical thinking. And so, if the pieces were laid out and I had either the evidence to draw my own conclusion or was given the sequence of it I could make sense, I would recognize that. It would still be hard for me to sit at times, but I would have responded better if I had known why. But none of my teachers ever did that for me.

Most often teachers assumed that Kelly was willfully ignoring their expectations.

To Kelly, there always seemed to be a set of unwritten rules that Kelly was punished for not following. For example, Kelly is a talented artist and, from a young age, had always used drawing as a way to work through a concept. Drawing for Kelly was a form of comprehension: "I think visually so I need to understand how things fit together." In college, Kelly was able to harness these strengths in her biology coursework. She created elaborate drawings and charts to work through complicated anatomy concepts (see Figure 11). However, during her K-12 years, teachers did not see this as a strength and, instead, routinely deducted points from assignments for "doodling."

Figure 11. *Kelly's College Notebook from a Biology Course*



This lined notebook in Figure 11 shows detailed drawings of an animal skull and jaw bones with words labeling the various elements of the bone structure.

Judy repeatedly defended her daughter against her teacher's deficit perspectives. She recalled a particular lesson in fourth grade, a writing assignment about trees. Kelly completed the assignment and then in the margins added a drawing.

> She had drawn these beautiful trees with fully formed leaves. I just thought this is amazing. The teacher was the weird one because this is great what she was doing. I didn't tell Kelly she shouldn't do that, but that it was wonderful.

Judy felt perpetually disappointed by Kelly's teachers who maintained such a narrow view of Kelly. Rather than see her artistry as a strength, the teacher viewed it as a deficit, an expression of her deviance. By punishing Kelly for "doodling," her teacher removed a way that helped Kelly regulate her attention and express her knowledge of a topic. It was around this time that Kelly's own sense of self began to shift.

In the beginning of elementary school, when Kelly was punished by a teacher or spoken to harshly, she interpreted the teacher as "mean." As she progressed through elementary school and experienced continued rejection by her teachers, Kelly began to internalize the rejection.

> I started to understand that teachers hated me. Around third or fourth grade, I figured out that I was the problem. Rather than the whole world is the problem I realized I'm the variable. I'm the problem. There was something in me that they didn't like.

Instead of a "them" problem, Kelly began to see the rejection as a "her" problem.

Elementary school was perhaps the most painful and difficult time in Kelly's school life. As she entered middle school, however, her relationships with her teachers became less taxing. Overall, Kelly found it easier to meet teacher expectations: "As I got older, it was easier for me to sit still." Kelly's relationship with her teachers became less antagonistic as she was better able to conform to their normative expectations of students.

Peer Relationships: Status Quo Rejection and Neurodiverse Connection

"The older everybody got, the more effective they got at conveying they didn't like me"

Kelly struggled to navigate peer interactions. In her preschool years, Kelly was often excluded from group interactions by her classmates. At the time, she did not understand or perceive the rejection and so would persistently try to connect. Her persistence coupled with her challenges in reading her classmates' social cues intensified their rejection of her. As Kelly entered elementary school, she became more aware of explicit rejection. Kelly's stock story about her

peers throughout much of her elementary school was that they thought she was "annoying" or a "know it all." It was not until around fourth grade that she developed true friendships with a small group of kids who all shared the experience of being outsiders. Almost all members of this friend group would later go on to identify as being part of the neurodiverse community.

Exclusion and Bullying

The center of social interactions in Kelly's preschool classroom occurred in the pretend house. Kelly loved the small wooden structure and was particularly drawn to the miniature real-life touches to the play kitchen, like the stove, sink, and doorknobs. During nap time, Kelly tried to sneak into the playhouse to sleep. She found the small space comforting. Her preschool peers often engaged in pretend family play in the tiny house. Kelly was eager to join in and asked her peers which family member she could play. When they responded that all the roles—mother, father, grandfather, grandmother, sister, brother, baby, etc.—"were taken," Kelly got creative: "Oh ok, I'll just be the dog. I would be the dog and just stay there while they were trying to play around me. I was happy and had no idea that I was being excluded."

At the time, Kelly considered herself to be part of the group but, in retrospect, she now understood it differently: "They didn't like me very much and found me off putting but at that age I couldn't tell." Part of the reason Kelly was unaware of the rejection was that at that age, much of the social life of young children was organized and managed by adults. Kelly was always included in adult-organized classroom birthday parties or neighborhood playdates. Young children, Kelly believed, also have a higher tolerance for a range of behavior: "At that age, kids will play together even when they annoy each other." With creative persistence, Kelly was able to join in the play of her peers, even if she was pushed to the periphery.

Starting in second grade, Kelly's peers transitioned from exclusion to more explicit bullying. Initially, Kelly interpreted the rejection as a kind of joke and liked the attention. For example, her peers weaponized Kelly's unpopularity by using the threat of Kelly as a way to bully other children. "They would try to bully the boy who was at the lowest part of the totem pole by saying I liked him. They all thought it was funny because no one liked me either." She attempted to join the game by going along with it and attempting to kiss and chase the boy.

During this time, Kelly loved the cartoon "Dexter's Laboratory" (1995), particularly the character of Dee Dee (Figure 12). The cartoon was about a young scientist, Dexter, who was repeatedly interrupted by his annoying sister Dee Dee. After Kelly mentioned this interest, I brought two graphic novels of "Dexter's Laboratory" and we read them together in the café. Looking through the novel, Kelly recalled how she impersonated Dee Dee to try to win favor with her peers. One of Dee Dee's signature moves was jumping onto Dexter and screaming "Hello!" Kelly copied Dee Dee's moves with her peers, jumping on top of them, grabbing them, and even pulling their pants down as a "joke." She thought these jokes were hilarious: "I would do that to people. It was very violent and dangerous, and people did not like me. Dee Dee was annoying and that was why her character was funny and cool, so I thought it was cool." Kelly's peers did not think it was cool. In her attempts to join in on the fun of being "annoying," she further isolated herself from others.

Figure 12. *Kelly's Icon in Second Grade, Dee Dee from "Dexter's Laboratory"*

In Figure 12, Dee Dee is showing her affection for her brother by climbing on him. The image shows a cartoon girl with blond hair and an exaggerated grin. She is balanced on top of the head of her brother, Dexter, who is visibly annoyed.

In an attempt to connect with peers, Kelly often shared her expert knowledge of animals or a favorite school subject. She was an excellent student and enjoyed reading. However, rather than impress her peers, she came off as a "know it all." As elementary school progressed, peer rejection became increasingly apparent to her: "At that point I started to realize that everybody didn't like me and the older everybody got, the more effective they got at conveying they didn't like me."

In kindergarten, Kelly spent much of her free time reading nonfiction about animals. There was a time when Kelly was specifically passionate about tapirs, a rainforest animal with a long trunk-like nose, which resembles a pig-like elephant (Figure 13). She brought her expert knowledge of tapirs to her play and acted out different facts she knew about these animals, including their role in supporting the production of chocolate. Often, this fantasy play was done alone. Attwood and Grandlin (2006) explained that engaging in elaborate solo symbolic play is common for autistic or Asperger girls: "When involved in solitary play with dolls, the girl with Asperger's Syndrome has total control and can script and direct the play without interference and having to accept outcomes suggested by others" (p. 5). Whereas her peers were more interested in elaborate fantasy play with invented rules, Kelly's play was what she described as "concrete pretend play" because she incorporated mostly real-world elements into her play schemes.

Figure 13. *Image of a Tapir, Kelly's Favorite Animal in Kindergarten*

Pretend play themes also offered a safe space for some of Kelly's preferred body movements, which were distinctly different from her peers' movements. Autistic girls, more than autistic boys, tend to be better at mimicking the play behaviors of their non-autistic peers and use pretend play as a way to "camouflage" or "mask" autistic symptoms (Dean, Harwood, & Kasari, 2017; Dworzynski et al., 2012; Hiller et al., 2014). As a child, Kelly toe-walked, bouncing on the tips of her toes when she walked. Adults and peers commented on her gait, so she turned her walk into an intentional game in which she pretended to be a kangaroo or a cat. When I asked her about this, I was specifically interested in whether she changed toe-walking into a game as a way to "mask" (Cook, Ogden, & Winstone, 2018) or cover up her difference.

> I made it into a game to both give an explanation to adults who would comment on it and be like, "Oh, are you like Tigger?" They would label it for me, so then I was like, oh, that's fun and a good game! Or I would inherently do it because it felt good and I loved animals and I knew that a dog or cat would walk on its toes, so then I decided, oh, I like that too, just like the animals. I'm making dog feet or tiger feet or kangaroo feet. I was really into pretend play. You know, so both.

Through pretend play, Kelly could conceal her differences.

Neurodiverse Friendships: Finding the Other Outliers

In fourth grade, Kelly formed a group of close friends for the first time in her life. The small group consisted of Kelly, two other girls, and a boy. The group shared a common bond; there was an outlier quality to each of the children that drew them to one another.

> All of my friends from when I was little turned out to be autistic, bipolar, ADHD, or gay. The kids who felt somewhat separated from normal society and everyone being too young to know why, but we knew that we were comfortable with someone breaking the norm in some way.

One of the girls from the group shared a passion for animals. She and Kelly spent hours talking about, drawing, and playing out animal themes. This girl also took on a nurturing role with Kelly and gave Kelly direct but caring feedback. She would ask her:

> "Why do you smell like mice?" And I would tell her, "Well because I have pet mice and I don't shower." Or she would say, "Hey, your clothes don't fit, try on this old dress of mine. Oh, it looks great on you."

For the first time, Kelly was receiving kind and direct feedback from peers that helped her to be more aware of how she affected others.

This strong friendship bond became invaluable to Kelly. Within this small friend group, Kelly felt understood and valued. For the first time in her childhood, she did not feel "too much" or "annoying." Many members of this friend group experienced a common neurodiverse experience. Although most often attributed to the autism community, the concept of neurodiversity extends to other disability communities, including people with Attention Deficit Disorder (ADD) and Bipolar Disorder (Armstrong, 2011; Silberman, 2015). As autistic writers Jen Elcheson and Anita Lesko (2018) explained, finding an autistic community can be a huge turning point in forming real friendships based on common interests and respect: "What is crucial is realizing that it's all about finding someone who accepts your difference and

appreciates you for who you are" (p. 70). Kelly was seen for the first time as an equal by this friend group.

Kelly's strong friend group became the deciding factor in her school trajectory. Frustrated with the controlling nature of her teachers, Judy had, by this time, come close to withdrawing Kelly from public school as she began to see public school as "not good for her." She had begun looking into private schools with more alternative expectations and assignments that would highlight Kelly's strengths and creativity. The only reason Judy kept Kelly in her elementary school was Kelly's small group of friends. "Her close friends were helping her. She finally had that peer support system and so I kept her there because I didn't want her to lose those friends." Friendships, not teacher relationships or learning, sustained Kelly.

Entering middle school was painful for Kelly as she was no longer able to rely on this core group of friends. The middle school drew students from several smaller elementary schools. As she and her friends entered middle school, each friend was placed on a different school team. Students stayed on the same team with the same students and teachers for all 3 years of middle school. Kelly and her friends were assigned to different teams; this meant Kelly never shared a class or teacher with any of her close friends. The intention of the teams was to encourage students to form new friendships while benefitting from the consistency of the same set of teachers. But for Kelly, who had struggled so intensely to form real friendships, the team structure was incredibly isolating: "It was a bad idea that was poorly executed." Kelly was able to maintain her relationships with these friends after school and on the weekends, but inside school, Kelly's daily life was lonely and very isolated.

In high school, Kelly reached a level of social ease completely new to her; she was reunited with her elementary school friends, was better able to read social cues, and felt more

capable of identifying and connecting with peers with shared interests. Kelly even began dating, navigating an entirely new type of social dynamic. Rather than respond with rules around curfews, Judy trusted her daughter's judgment. She spent time with Kelly's friends and boyfriends and enjoyed their company. When all of Kelly's friends entered a rebellious phase and pulled away from their parents, Kelly remained even-keeled and close with her mom. Judy described Kelly's teen years as uncharacteristically calm: "She was really easy to get along with." Judy prioritized getting to know Kelly's friends and boyfriends and did not feel a need to assert power over her teenage daughter. Kelly appreciated and responded to her mother's trust in her: "Of all of my friends, my mom let me do whatever I wanted. All my friends had a rebellious phase, but I didn't have anything to rebel against because all of my mom's rules were very reasonable." The strength of Judy and Kelly's relationship, Kelly's newfound social comfort, and Judy's position at a local college made staying in town for college the best option for Kelly.

Autistic Mentorship

"It's so powerful when someone understands you"

As Kelly entered adulthood, she had a well-developed sense of self and new tools to know how to navigate college and later adult employment. In adulthood, Kelly worked with disabled children both in school settings and as a nanny. Equipped with this self-knowledge, she returned to school settings, but this time as the teacher. As a self-actualized autistic woman, she was able to form new connections with students and ultimately became the support system for others that she herself did not have from teachers.

College became the place where Kelly was able to fully embrace her autistic identity. She entered college identifying as autistic and received a clinical diagnosis during her freshman year. She studied her two passions, science and art. She moved in with her autistic boyfriend,

Cameron, and began presenting at autism conferences. Some of the same peer dynamics of exclusion resurfaced, but being in possession of more self-knowledge, Kelly was able to unpack why the dynamics occurred and did not internalize the rejection. One particular peer in her phronesis pathology course interpreted Kelly's confidence and participation level in class as a personal attack. "If she said something factually incorrect, I would correct her. I was never rude about it, but that made her hate me." In this class, there was another girl, Emily, with whom Kelly got along and who this peer equally disliked. Kelly immediately saw similarities between them.

> Emily was even more unfiltered autistic. I had already had a year of knowing I was autistic and was working on not being annoying, but she was still a full Hermione Granger. Finally, I just asked her, "Do you have an autism diagnosis because if you don't, you should get one."

The two spent a day together in a local bookstore reading Toni Attwood and Temple Grandlin's (2006) *Asperger's and Girls*, the book that Kelly had found so influential to her understanding of herself. Emily excitedly devoured the book and saw herself deeply reflected in the descriptions. "She got so excited and she went home from the summer field school with a diagnosis. I'm very proud of that." As a teen looking to see her own experiences reflected back at herself, she found this support online through other autistic women. Now Kelly was that guide for Emily.

After graduating from college, Kelly worked in several different jobs with young children with disabilities. In her first job, she worked in an Applied Behavioral Analysis (ABA) preschool for autistic children (for a further explanation of ABA, please refer back to page 50). Kelly is not a fan of ABA: "The hardest part about that program was the ABA, but as soon as I was done with the training, I stopped doing the bad parts of ABA. I would never hold a kid's hand to do anything." One student was particularly difficult. This child was often paired with Kelly: "He liked me and would behave better for me and wouldn't flop out of his chair because I treated him

like a person." It was important to Kelly that she treated the students with respect. She would speak to them "not in that annoying high praise voice," but in a natural tone. Kelly described her experiences with teaching with obvious signs of love. She smiled broadly as she recalled a particular student's love of Cookie Monster or another student with a motor impairment who used a sign to request *Twinkle Twinkle, Little Star.* I asked her what it was like to be in the role of authority, the role of a teacher:

> I really liked being the teacher because it meant that I got to be the one that talked to them like people. I understood them and would say, "Oh yeah, I sometimes feel like that." It was also super frustrating because I would see the other teachers just not understanding the kids and doing the wrong things all of the time.

Kelly's capacity strength-based approach towards these students was an opening for possibility in their educational trajectory.

One of the trends Kelly noticed as a teacher to autistic children was the way in which teachers attached meaning to autistic children's behavior. For example, Kelly noticed a big difference in the way young autistic children's play is viewed versus the play of non-autistic children. When Kelly was very young, she loved to engage in repetitive play that involved sorting, organizing, or lining up objects. As an only child, her mother appreciated the way she engaged in solitary play.

> I was really good at playing independently because I was an only child. I would like to go outside by myself in the backyard and pick a bunch of leaves and line up all the different kinds of leaves and entertain myself.

In school, she enjoyed lining animal figurines and labeling them, or sitting in the ball pit, picking out each colored ball and labeling it by color. She would do this for an "unlimited amount of time." Because Kelly did not have a diagnosis at the time, her teachers did not view her play through a pathologizing lens.

> The teachers saw this as me being really smart and knowing my colors. That is how adults will see kids who aren't diagnosed differently. They pathologize the behaviors of the kid with a diagnosis and redirect the kid away from what they are doing. This kind of play is seen as a symptom of fixation and repetition and is viewed by adults as something that is preventing autistic kids from connecting socially. Instead, this kind of play is intrinsic to their personality. It's the best way to connect with other people. I remember having a long discussion with another little girl about the difference between yellow and white. I would engage with the other kids in the ball pit around my interest in colors. They would say "What is that?" and now the play is interactive.

Although her relationship with her preschool teachers was overwhelmingly negative, they also viewed Kelly's play as meaningful and an expression of her competency and intelligence. Because she was free from a diagnostic label, she was able to enjoy her categorization and repetitive play.

Working with young autistic children highlighted for Kelly the ways in which she both suffered by not having a diagnosis and benefited by it:

> The whole early diagnosis versus. late diagnosis thing is that there are pluses and minuses. I was never told how to play or that I was playing wrong. The WAY that I played with toys was never criticized and was never controlled, whereas people I know that got really early diagnosis were diverted away from the way they wanted to play with things and were redirected and taught how to play. That didn't happen to me. I didn't get the support or treatments and I was basically treated like a horrible person, but at least I was allowed to play how I wanted.

Kelly cherished the opportunity to do both for her students. She provided them with the support they needed and allowed them to pursue and express their interests free from scrutiny.

Kelly's most significant teacher/mentor relationship occurred outside of school, when Kelly worked for a year as a nanny for a young boy with sensory and emotional challenges. At the age of 8, he had already been kicked out of several school programs for aggression. Kelly formed a deep connection with the boy and was deeply proud of the work they did together.

> The best thing I have ever done in my teaching career is working with that kid. He was the kind of kid that like NO ONE in his life understands him. NO ONE. He's being raised by a single dad who is pathologically Midwestern and is sooo polite and cares so

much what other people think of him and he does things where he often misses what's going on underneath with his son in favor of the path that is socially smoother.

Kelly worked hard with this boy to help him understand his emotional reactions. Instead of judging his responses, she would co-regulate with him by trying to explain what occurred.

> He would lose control of himself all of the time. Like a really zero to sixty personality. Very volatile and reactive personality. But I didn't blame him for it. Sometimes it was really bad and he would bite me all over and, yeah, that was terrible. And I would say, "That was really scary for both of us. I didn't like that, but are you ok now? We're safe. You didn't kill that kid that you were mad at. We're home now and we're safe. Let's just go watch TV and have a snack and unwind."

Kelly saw herself as an important ally to the child. His father, who Kelly described as an exceedingly polite Midwestern type, was kind but very concerned about the opinions and reactions of other people. He constantly apologized for his son's behavior. Kelly wanted the boy to know that she was "always on his side."

When Kelly was little, all she wanted was an adult to explain why things were the way they were, so for this boy, Kelly worked hard to explain what he was experiencing during his meltdowns.

> Sometimes your brain gets so lit up with everything that's happening that it can't really handle it and you're still in there and everything is fine, but your brain is just yelling at you and it gets really weird and you just need a big hug and a dark room for a minute. Kids like that do not understand and blame themselves. They know they are the problem and that no one else is acting like this.

Kelly stayed in touch with the boy for years after she stopped working as his nanny. At least once a year, usually on his birthday, she visited him. As she talked about him, she became emotional and her eyes welled up a bit.

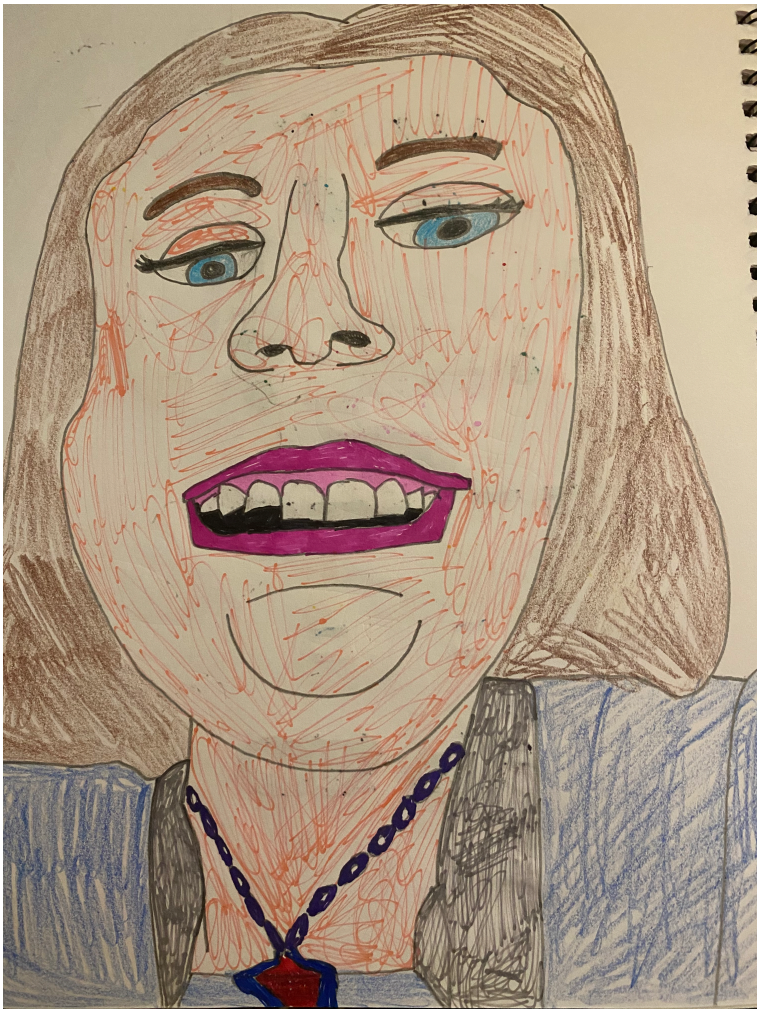
> K: I just really like the idea that although his life is still sooo hard and he doesn't have anyone who is on his side now, there is this span of time from when he was seven to eleven that he has a memory of one adult who was on his side and who understood him. That sort of thing meant SOOO much to me at that age.
> I: Did you have anyone like that in your life?
> K: The closest thing to that for me was my mom.

Kelly's mother served as an essential ally in her life, someone who could understand her daughter's perspective and see her strengths and unique gifts. Kelly then in turn got to serve this role for other neurodiverse people and help support them in their own journey to find community and connection.

FOREWORD TO CHAPTER V

Below is a self-portrait of Zula, a White woman in her 20s with pink lips and blue eyes. She has shoulder-length brown hair; she is wearing a blue shirt and has a purple necklace with a purple stone.

Figure 14. *Zula's Self-Portrait*



Zula is a 26-year-old, autistic, White woman with thick long brown hair that she wears pulled back in a low ponytail. I first met Zula at a pastry shop with her mom, Patricia. Zula wore a completely purple outfit: purple coat, purple scarf, purple sweater, purple necklace, and purple sneakers. I later learned that purple is her favorite color. Although Zula appeared quiet and shy

during our first meeting, she agreed to meet with me again the following Monday and we exchanged numbers so we could text easily. I offered to meet her outside of her job at a local thrift shop at the end of her shift. Zula instead suggested, “Let’s meet at the Starbucks at the corner of my mom’s building.” Zula’s comfort with new people is slow to build. During our first few meetings, Zula appeared nervous, communicating primarily through body language, head nods, and smiles, with occasional short phrases sprinkled in like “I don’t know” or “Maybe.” As our relationship grew, Zula appeared increasingly comfortable, initiating conversation and regularly asking me about my life—specifically my wife, my daughter, and, most often, my cat Orlando.

Zula was raised primarily by her mother, Patricia. For a period of time, after Patricia’s divorce, Patricia and Zula lived with Patricia’s parents. As a nurse, Patricia worked long shifts and Zula’s grandmother often stepped in to play an important caregiving role for Zula throughout elementary school and middle school. Since then, Zula has maintained a close relationship with her maternal grandparents. Throughout her schooling, with the exception of preschool, Zula attended special education public school programs where she was often the only or one of two girls in her self-contained classrooms. The term “self-contained,” which Patricia used to describe Zula’s classroom experiences, meant that Zula’s classmates were all students with diagnosed disabilities. Zula’s classrooms most often consisted of eight students, one teacher, and one teacher aide, which Patricia —drawing on the terminology of the local school district—referred to as an “8:1:1” classroom.

Zula lives in an apartment that she shares with Ben, her husband of 3 years. The couple enjoys going to the movies and making dinner together every night. Zula works afternoons, 4 or 5 days a week, at a neighborhood thrift shop where she has worked for several years. After work,

Zula walks four short blocks from the shop to her mother's apartment where she once lived. Although she has her own apartment, she spends the majority of her free time at her mother's so she can play with her four cats: Tracy, Charlie, Zorro, and Sylvester. Patricia and Zula have a very close relationship and enjoy going shopping together, watching TV, and getting their nails done. Routines are important to Zula and she organizes her days by her weekly activities, which include her Tuesday evening art class; Wednesday evening dinner club; and Friday dinner with her husband, mother, and grandfather at a favorite Italian restaurant. Zula always orders the chicken parmesan. Our research meetings, which occurred weekly on Mondays at 4:00, also became an important weekly routine for Zula and she regularly texted me Sunday evening to confirm our meetings for the following day.

I learned about Zula in unpredictable ways, in pockets of time. Here is an excerpt from a conversation in which I learned about her evening plans with her husband, Ben. It occurred while we were both sketching together.

R: Do you have any plans tonight?
Z: I'm having dinner with Ben.
R: That's great. Where are you going?
Z: Ben's getting me Halal food for dinner.
R: He's picking it up for you?
Z: Yeah, and we're watching *The Bachelor.* (switches back to discussing her own drawing) Now use the green.

This is a fairly representative sample of our conversations and the way we shared space. Zula seemed the most comfortable in conversations with space for silence where she drew or did something on her phone. Peppered into our drawing sessions were parts of her life that she would share with me.

Zula's narrative is co-constructed and unfolded out of the collective effort of Zula, her mother, and me. Co-construction has a legacy in the field of disability studies research. Philip M.

Ferguson (2001) described the way that he "reads" the winks and twitches of his cognitively disabled son: "Ian's story must be explained by those around him" (p. 136). Like Ferguson, Patricia provided essential narrative structure and context in the telling of Zula's school story as well as her own experiences of motherhood. Mother and daughter are extremely close and Patricia's perspective on Zula is invaluable. Interwoven into Patricia's stories are Zula's own perspectives on particular events.

Throughout this chapter, I make my own perspective more visible through the use of first-person vignettes (vignettes are marked by italics). These vignettes explore my worries, wonderings, and moments of feeling lost or confused during the research process. I selected these vignettes because they represent a "glow" (MacLure, 2013) from the research, a moment that stuck with me, that marked a turning point or a moment that continued to linger long after the research meeting ended. My particular framing of vignettes was inspired by the work of Wendy Luttrell (2010), who described "reflexive knowing" as much more than simple researcher self-reflection. Through "reflexive" vignettes, the researcher can make "the research process and decision making visible at multiple levels" (p. 4). In crafting this chapter, my concern always was the balance of co-construction and voice. Zula was the main character in her own story. I wanted to prioritize her ways of knowing and her perspectives. My hope is that Zula's self-advocacy and authorship are highlighted in the vignettes and that her way of expression is honored and respected in my retelling.

Chapter V: ZULA

This chapter has three sections. The first section is devoted to Zula in the research space and explores the ways she expressed herself, shared her memories and preferences, and advocated for herself. The second section explores Zula's school history and is predominantly told from her mother Patricia's perspective. In the last section, I return to Zula's life in the present day to explore themes of connection and community in adulthood.

Communicating with Zula

Zula and I met a total of 14 times over the course of 7 months, which resulted in approximately 20 hours of time together in person. During our meetings, we talked, played with apps on her phone, drew, read comic books, watched SpongeBob SquarePants cartoons, ate ice cream, attended a holiday party, ate Thai food, sent each other texts, sat in long periods of silence, and talked a lot about cats. After my last in-person meeting with Zula, I interviewed Patricia via Zoom (due to the pandemic) for a little over an hour about Zula's schooling experience. Zula declined to join the Zoom conversation but confirmed that it was okay for me to speak with Patricia. Over the 7 months, Zula communicated her preferences and advocated for herself in a variety of ways. As the research project evolved, Zula and my relationship grew to the point that she could express a range of emotions, including anger and frustration.

Over the course of several months, I learned to read Zula's body language. Ferguson (2001) used Geertz's (1973) conception of "thick description" to explain the importance of reading the body; "even the simplest physical behavior can quickly become embedded in layers of cultural interpretation as we thicken the context surrounding the behavior" (p. 133). When Zula felt excited about a specific topic of conversation, she often rocked back and forth slightly and rubbed her thighs with her palms. In these moments, she also looked directly at me,

repeating a phrase or word and elongating the sounds. There were times when the conversation drifted into subjects Zula disliked; in those moments, Zula appeared to withdraw. She displayed the same body movements, but at a slower pace, and rather than look at me, she looked down at the table.

I first noticed these changes in her demeanor after returning to listen to a meeting I had recorded. For the majority of that meeting, Zula gave short answers to my questions about her school memories: "I don't remember" or "I'm not sure." When the conversation shifted to one of her passions—her cats—her voice became animated, and upon learning the name of my cat, Orlando, she happily repeated his name with emphasis: "ORRRlando!!!!"

R: After work what do you usually do?
Z: I usually go to my mom's house.
R: Pretty much every day?
Z: Yeah, yeah.
R: Is she usually home?
Z: She's usually home with our four cats.
R: She has four cats?
Z: Yes!!! (excitedly)
R: What are their names?
Z: Tracey, Charlie, Zorro, and Sylvester.
R: Very cute. I have a cat too.
Z: You have a cat?
R: Yeah, but he's kind of grumpy, though. He does a lot of swatting.
Z: What kind of cat?
R: He's all black with a little white tuft on his chest and a white paw.
Z: What's his name?
R: Orlando.
Z: ORRRlando!!!! (smiles and rubs her hands on her thighs excitedly)
R: Yeah. You like pets a lot?
Z: I like pets a lot! (nodding enthusiastically)
R: Do you have a pet at your apartment?
Z: I had a pet a long time ago.
R: Ok.
Z: I have a Vinny, Mingy, Murry, and Tigger and George and Minnie and Howard.
R: That's awesome. I like cats too. Four cats. Do they fight?
Z: Yes, a little bit fighting. Sylvester and Zorro.

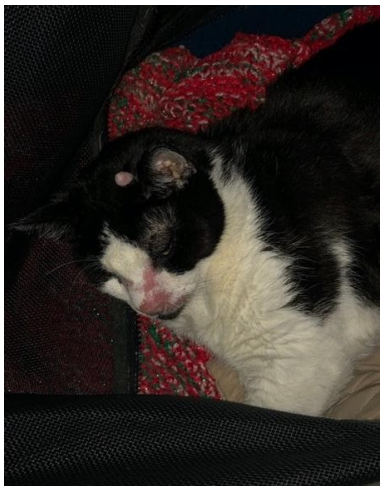
For the first time in the meeting, Zula initiated a question ("What kind of cat?") and shifted the dynamic from interviewer/interviewee to a conversation between two people who like cats. Zula was eager to learn more about Orlando; the conversation moved from stilted questions about her schooling memories (generated by me) to Zula excitedly pulling out her phone and showing me pictures of her cat. She was delighted to see pictures of Orlando as well.

Figure 15. *Zula's Mother's Cats*

Tracy

Charlie

Zorro



Sylvester

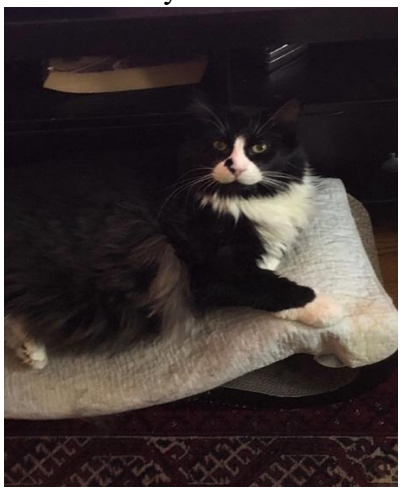
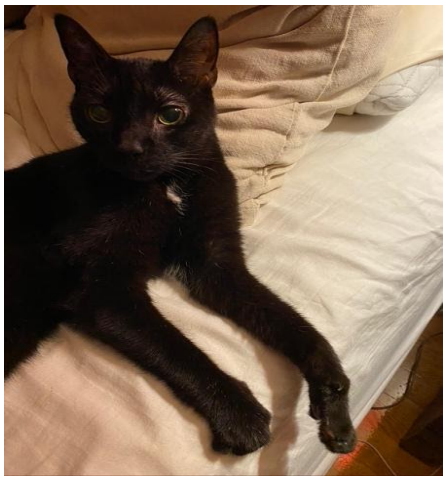


Figure 16. *My Cat Orlando*



Over the course of our time together, I kept a list of the things that sparked Zula's interest and gave her joy, and I made a commitment to prioritize these interests in our time together. They included:

- Cats
- Hanging out at her mom's apartment with the cats watching TV or the news
- SpongeBob SquarePants and Powerpuff Girls
- Drawing, painting, and recreating preferred cartoon images
- Dates, especially people's birthdays and anniversaries
- Going out to eat (especially Italian or Thai food) or getting iced coffee (Starbucks)
- Friday weekly dinners with her family at a favorite Italian restaurant
- Lunches with her grandfather
- Cooking, shopping, going to the movies with Ben
- Hanging out with her mom (shopping, drinking hot chocolate, getting nails done)
- Attending art class, dinner club, and eventually Phoebe's House (a social club for autistic women)
- Purple clothing and jewelry
- Musical artist Carly Simon
- Word puzzle games on her phone
- Asking about my daughter
- Routines at the thrift shop (her job schedule, her boss, holidays at the thrift shop)
- Lists, including preferred people, favorite items, or schedules

My list became a guide, gradually influencing the development of our research meetings. I also made more of a commitment to exploring multimodal ways of spending time together. I knew I needed to incorporate visual elements into our meetings to prioritize her meaning-making

and preferences for communication and expression. A few months into our meetings, I introduced the concept of doing a self-portrait. The following vignette narrates this particular research meeting and the ways that Zula asserted her own opinion and perspective into our research relationship.

"I want to do this. I'm not interested in a self-portrait today."

As I walk to meet Zula at the Starbucks, I hustle a bit. Its 3:55. I'm almost late. Time and consistency are important to Zula and I knew if I were late, it would cause her some anxiety. I arrive right at 4:00. I am excited for our meeting today. This is the fourth meeting, and I am excited to try something new today. Zula has a passion for drawing and often shows me pictures of her illustrations on her phone. Her favorite thing to draw is cartoon characters from preferred shows such as SpongeBob and Powerpuff Girls. I feel excited to incorporate this visual arts element into our meetings and think that doing self-portraits can be a rich way to explore her perception of herself. I am curious to see how visual arts elements can open up new ways of sharing information with one another. The previous week I pitched her the idea of doing a self-portrait, she was enthusiastic and together we ordered some art materials on my phone, which included colored pencils, a purple pencil sharpener, fine-tipped colored sharpies, and two sketchbooks.

As I walk in the door, I see Zula immediately. It is a very small Starbucks with only three or four tables. Zula is seated on a bench playing a word search game on her phone. She is wearing her favorite purple coat, a long purple scarf, a long necklace with a purple gem. She smiles as I put down my bag and she is eager to get going. "Did you bring the sketchbooks today?" she asks, and when she spots them in my bag, she adds, "I'd like a small, iced coffee

with skim milk please, Rae." "Sure," I respond and put the art materials on the table before heading to the counter to retrieve our usual order of a small, iced coffee and a Spindrift seltzer.

When I return to the table a few minutes later, Zula is already busy drawing. Balanced on the top of her sketchpad, her phone shows a Google image picture of the cartoon figures from the Powerpuff Girls (see Figure 17)*. She uses the image as a guide for her own rendition of the characters. I sit for several minutes arranging my own supplies on the small round table. The seating arrangements are awkward, and I anxiously shift in the small stool. My arm is almost brushing the shoulder of the person sitting at the next table. I barely have room for my research notebook and the tape recorder I always use to record our conversations. I am unsure of how to proceed. Zula is laser-focused, drawing with confidence and quietly talking to herself: "Oh, ok, yeah. Ummm yes, a curve here. Maybe pink…." I finally speak up to interrupt her flow: "I like your Powerpuff Girl picture. Do you think after Powerpuff Girls, we can do a self-portrait?" She responds, "No. I want to do this. I'm not interested in a self-portrait today." I sit for a moment feeling unmoored. WHAT AM I DOING?*

Just then, a woman sitting two chairs away calls Zula's name. She is wearing a large black hooded sweatshirt with the words "New York Fucking City" scrawled across it and she is holding the leash of a dog…. A dog in the middle of a Starbucks. Zula looks up from her drawing and calls the dog's name, "Maggie! Yes Maggie! Hello Maggie." The dog crawls under the bench to reach Zula and excitedly jumps on her lap, which sends the art materials cascading onto the floor. Again, I ask myself: WHAT AM I DOING?

Zula knows this dog well as its owner lives in the same building as Zula's mother. The two women engage in friendly conversation and the dog jumps happily into Zula's lap. In this moment, I pull back from the scene to observe myself. I am in Zula's world. This is her comfort

zone. This is her coffee shop. Her regular order. Her neighbor and her favorite neighborhood dog. I'm a visitor here. I'm the one who will have to let go of my preconceived notions of what this research will look like. As I watch Zula completely at ease petting the dog and chatting away, I start to laugh at myself. What is wrong with me? Why am I so uptight?

After a few minutes, the dog crawls back under the bench toward the owner. The neighbor and Zula end their chat and the woman returns to her coffee. Zula immediately returns to her drawing. I sit quietly and sip my seltzer. What if I just start to draw too? I open a sketchbook and am immediately aware of my lack of creativity. I have no idea what to draw. I look up at Zula and am struck by the contrast of experiences in that moment. As she draws, she is completely confident, never erasing, never hesitating, approaching her drawing with purpose and passion. I notice that she is not rubbing her thighs at all, something she does when she's anxious or thinking of something unpleasant. I reflect on the role reversal occurring in this moment. She's so at ease with drawing and I'm so NOT—I have no skills; I don't know what I'm doing. Is this in any way the way Zula feels when I'm asking her interview questions? There's a code switching that happened today.

Finally, I decide to draw a cartoon picture of Little Red Riding Hood. It's in my mind from my daughter's Halloween costume. I begin to sketch, and Zula breaks her focus to smile at me and give me some encouragement: "Oh, that's very good, Rae." After a few minutes, she flips a page and finds a new image on her phone. "I like SpongeBob," she tells me." I'm starting to feel more at ease. I'm just going to follow her lead. Wasn't this the point of the research? I'm supposed to spend time with her and see what she enjoys? See what brings her joy? I too look for a picture of SpongeBob. It turns out it's the same picture. We sit together for 30 minutes, quietly drawing.

Our meeting ends, and on my walk to the train, I receive a text from Zula. "When is your birthday?" she asks. I may not know what I'm doing in terms of my research questions, but something is working. Zula loves birthdays and if I've made her birthday list, I know that she is starting to trust me. I can almost see her receiving my response and her carefully entering a reminder into her phone. What am I doing? … We're building a relationship.

Figure 17. *Google Image Search of Powerpuff Girls*

Figure 18. *Zula's Drawing of Powerpuff Girls*

Figure 19. *My Drawing of Little Red Riding Hood*

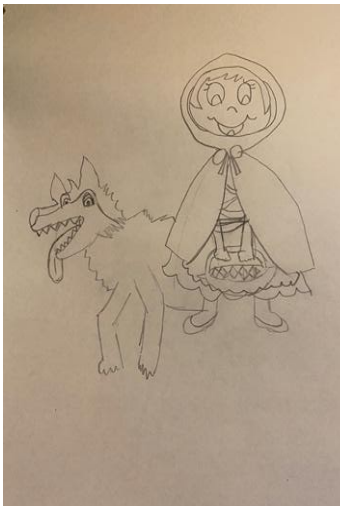


Figure 17 is a Google image of three cartoon characters, the Powerpuff Girls. One girl has black hair and green eyes, one girl has orange hair with pink eyes and a large pink bow, and the third girl has blue eyes and blonde hair in pigtails. All three characters have large eyes and smiles. Zula used the Google image as a template for her own drawing. Figure 18 is the drawing that Zula made of the Powerpuff Girls based on the Google image. The picture is hand-drawn with a pencil and half-colored in with marker. Figure 19 is my pencil-line drawing of a cartoon image of Little Red Riding Hood and the Wolf.

Figure 20. *Google Image of SpongeBob*

Figure 21. *Zula's Drawing of SpongeBob*

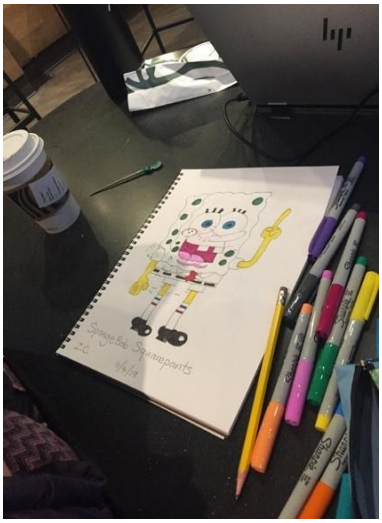
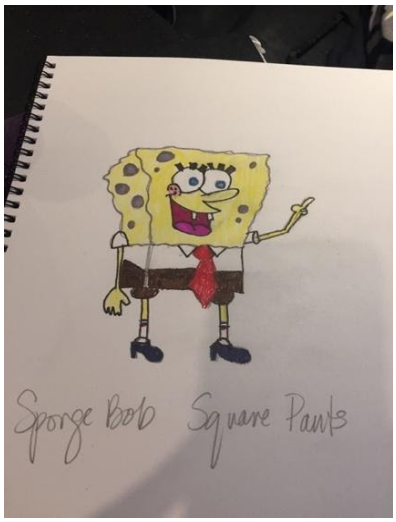


Figure 22. *My Drawing of SpongeBob*



Zula and I drew these sketches after the Powerpuff girls. All drawings were done within the same 1-hour meeting. Figure 20 is a Google image search of SpongeBob SquarePants. It shows a square yellow cartoon figure with large eyes, a red tie, brown pants, and a white shirt. The character is smiling and pointing his finger in the air. Figure 21 is a line drawing of SpongeBob SquarePants done by Zula and shows a square sponge cartoon character smiling with his finger pointed. It is partially colored with a marker and them drawn with pencil. Figure 22 is the same picture drawn by me; it is fully colored in with colored pencils and reads "Sponge Bob Square Pants."

Following Zula's Lead

There were many more moments like the one described above in the coffee shop, moments in which Zula clearly communicated her preferences. Her act of assertion was simply doing something else, something more to her liking; in doing so, she established her own power in our research dynamic, sending the message, "This needs to work for me." There were moments when I felt so present with Zula, and there were other moments when I felt

overwhelmed and lost. I worked hard to prioritize Zula's interests, to build rapport, and to be in the moment. But there were other times when we sat together, silently playing a word search game on each of our phones, and I couldn't help but return to the questions: "What am I doing? Have I lost the thread of the research?" I returned to the work of disability studies scholar Dan Goodley (1999) who warned, "Disability research *with* participants can fall into research *on* participants—when the only person benefiting is the researcher and their career aspirations" (p. 43). Goodley explained that critical self-reflective work on the part of the researcher is essential to preventing this one-sided dynamic. I continued to go with Zula's interest and prioritized her joy over adherence to a research agenda specifically tied to schooling.

The more I let go of control, followed Zula's lead, and prioritized her interests, the more surprised I was by the way our time together shifted in unpredictable and non-linear ways. Just when I felt most unsure of our connection to my research topic, we found ourselves back again exploring issues of identity or schooling. The week that followed the vignette above, I met Zula at 4:00 outside of her workplace, as she requested. As soon as she saw me, she surprised me by saying, "Let's go get hot chocolate and draw self-portraits. I feel like I want to do that today." We spent the hour drawing self-portraits, sipping hot chocolate, and humming along to the Christmas music that blasted from the speakers of the donut shop. When I envisaged this research activity, I planned to engage in a "draw and write" approach where the researcher uses the self-portraits to ask the participant questions about their gender, race, or disability identity (MacGregor et al., 1998; Mitchell et al., 2011; Ozden, 2009; Wood et al., 2012). Instead, we spent this hour together drawing our self-portraits, sipping hot chocolate, sitting quietly.

Figure 23. *Zula Using a Selfie to Start Her Self-portrait*

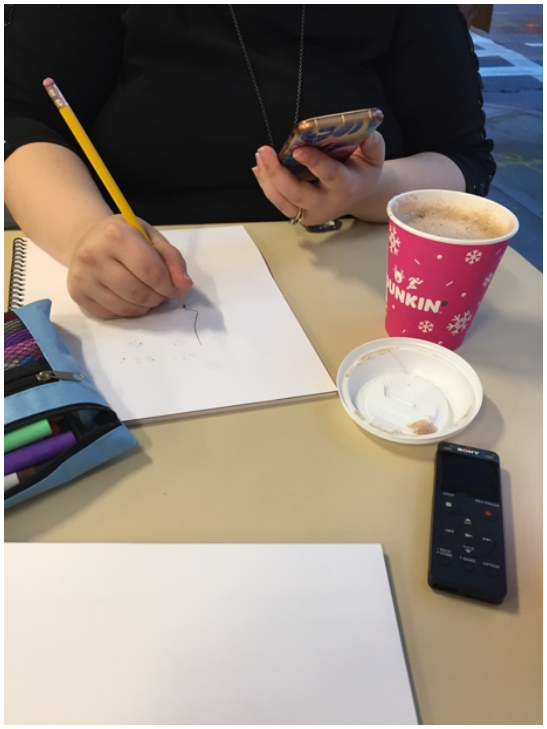


Figure 24. *Our Self-portraits*

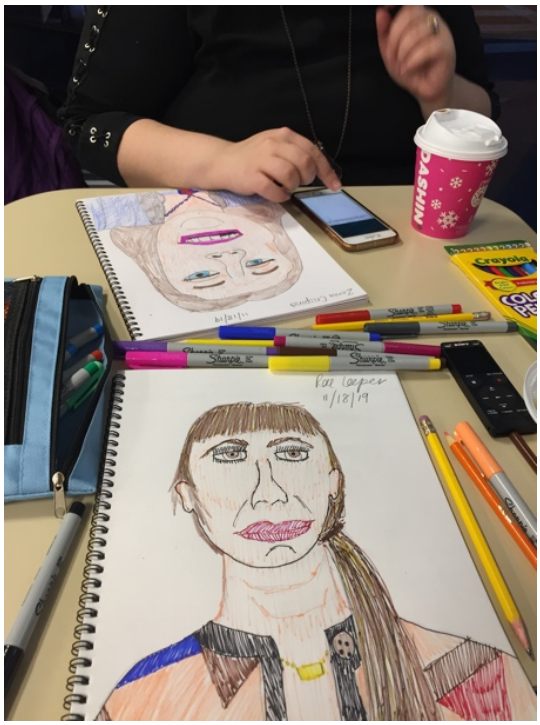
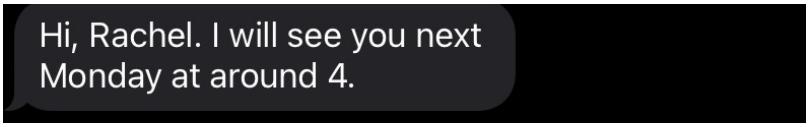


Figure 23 shows Zula's hands and arms as she is drawing in a sketchpad and holds her phone. There is a pink-cupped Dunkin Donut's hot chocolate on the table and drawing materials. Figure 24 is an image of two self-portraits hand-drawn with colored pencils and markers. These are described in more detail next. Figure 25 is a hand-drawn self-portrait that Zula created with markers and colored pencils. It shows a White woman in her 20s with pink lips and blue eyes. She has shoulder-length brown hair; she is wearing a blue shirt and has a purple necklace with a purple stone. The last figure, Figure 26, is my self-portrait, drawn with colored pencils and markers. It shows a White woman with brown eyes and long brown hair that comes down on the side. I am wearing a color-block sweater and a gold necklace.

Figure 25. *Zula's Self-portrait*

Figure 26. *Rae's Self-portrait*

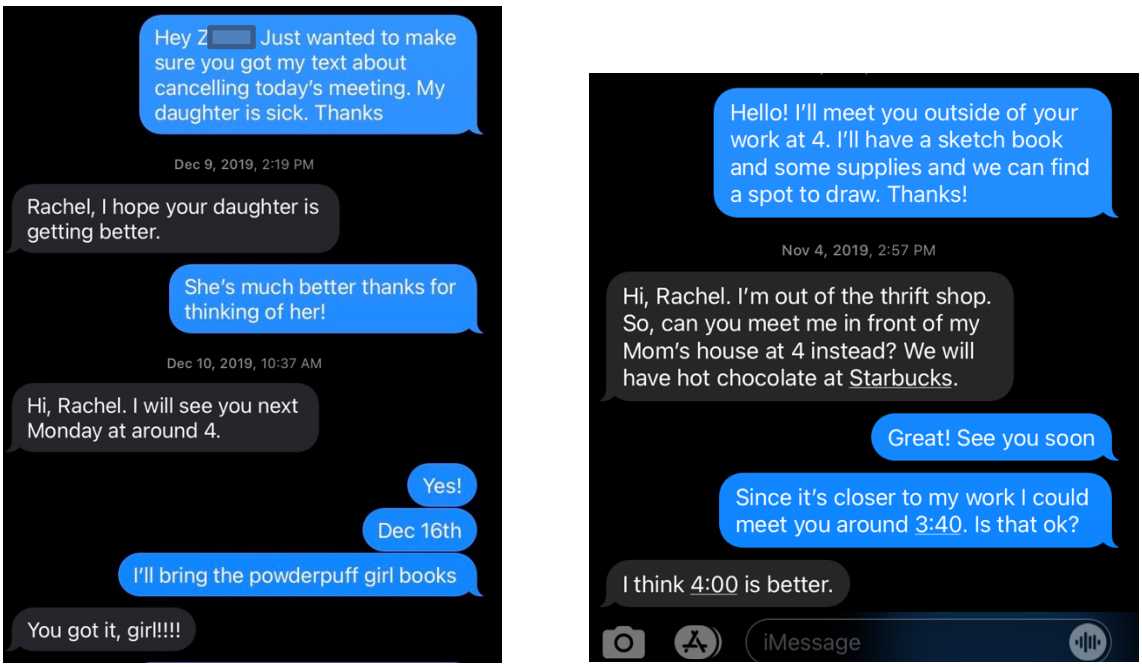
Text Messaging



Text messaging proved to be an important part of our relationship and it was often via text that Zula would assert her feelings about an activity I suggested, a schedule change I requested, or a change of her own she wished to make (for example, instead of an iced coffee, she requested a hot chocolate). There were times when Zula agreed to something in person but would later text me to clarify that she did not want to do a particular research activity or, in fact, wanted to meet at a different location. One day, I attempted to adjust our meeting from 4:00 to 4:15; via text, Zula answered, "I think 4:00 is better" (Figure 27).

Zula, however, was forgiving and flexible when changes to the routine involved personal responsibilities. For example, on a few occasions, I needed to cancel on the day of our meeting because my young daughter was sick. Zula was always understanding and often inquired about my daughter's health after a missed meeting. I saw these as moments of connection and care. After confirming that my daughter was on the mend, Zula was quick to confirm a return to the regular Monday meeting schedule (Figure 27).

Figure 27. *Text Messages about Appointment*



Over time, Zula's assertiveness over text began to transfer into our in-person interactions. For example, one day I suggested that we could do some portrait drawings of her preferred classmates and teachers.

R: I'm wondering if you'd be interested in drawing a picture of Miss Alice or some of the kids you talked about.
Z: NO.
R: No?
Z: No.
(after two minutes of silence where Zula is drawing in a sketchbook)

R: How about if I found an episode with Powerpuff girls and we watched it together?
Z: SURE!
R: You'd like that?
Z: Cool. Sure.

Zula's ability to communicate negative feelings clearly, specifically disappointment and anger, became apparent during one research meeting where I made a series of mistakes.

"You're late!"

"*Where are you!!??" is the first thing I hear when I pick up my phone. Zula is angry and I can hear her frustration with me in her voice as I respond, "I'm here at the Starbucks. Don't you see me?" I'm so confused. I look around the tiny Starbucks where I've been sitting for 20 minutes. Our plan was to walk to her apartment and watch a SpongeBob SquarePants episode together. I had done my research to prepare for our meeting and was excited to share with her a particular episode, "SpongeBob Goes to Boat School," as a way to connect to her own schooling memories.*

"I'm here waiting for you. You're late!" She is really angry. I have never heard that frustration before in her voice. She speaks loudly and quickly, almost yelling, "I told you the Starbucks on Jefferson Street!!!"

I was at the wrong Starbucks. I forgot that we had planned to meet at the Starbucks near ***her apartment, not her mother's.*** *I apologize and hustle out of the door. It is pouring rain and I walk briskly the 10 blocks to the right location. When I arrive and Zula and I make eye contact, I see a look of relief spread across her face, but I can also still see her lingering tension of frustration around her mouth. "I'd like an iced coffee with skim milk, please," she says quickly. When I return to the table with her drink, I am hopeful we are on a path to reset. I'm excited to get going, "Well, should we go to your apartment?" She doesn't move.*

Z: Let's watch SpongeBob.
R: Great. I've got an episode ready for us on my laptop.
Z: Let's watch it here.
R: Here? Oh, I thought we were going to your apartment.
Z: No.
R: Ok. I'm glad you're telling me that.
Z: Let's watch it here.
R: Here? At Starbucks?
Z: Yes.
R: Well, I don't have headphones and I don't think we can watch it without headphones.
Z: Let's watch it anyway.

Zula is crystal clear about her boundaries and her preferences. She does not want to go to her apartment. She wants to watch SpongeBob here in this coffee shop. I spin a bit in my head. Not sure what to do. How did I make such a mess of this situation?

Zula sits completely still, staring at me for several minutes with a look of expectancy. Finally, I break the silence, "Oh ok. I can go look for headphones and you can watch on my computer and I can use my headphones and watch on my phone." "Yes! Good idea!" she declares and the creases in her forehead melt away, her lips loosen around the edges.

At this point, it is absolutely pouring outside. I visit three different drug stores before I find the right pair of headphones that connect to my aging laptop. When I return, I plug in the headphones and I open the episode I downloaded. Zula looks disappointed and anxious. She begins to rock back and forth in her chair and rubs the top of her thighs with the palms of her hands. "We will start episode one, season one." And so, we did just that.

After getting onto the coffee shop WIFI and a few attempts, I am able to successfully sync my phone and the computer. We watch side by side on two different devices with our headphones. When the theme music starts, she smiles and looks at me, "I can hear it!" Her face lights up with excitement, and seconds into the episode, she's audibly giggling. This is the first time I have heard her laugh. I've seen her smile or look at ease while drawing, but here, in the

right Starbucks, with the rain outside, watching the first episode of the first season of her favorite show, she is belly laughing. As the episode progresses, Zula rocks in her chair more rapidly. The pattern as she rubs her hands on her thighs changes from back and forth to a circle. Her shoulders relax and she leans towards the screen with a look of pure joy (Figure 28).

Figure 28. *Three Images Showing Laptop Playing SpongeBob SquarePants*

The three images show a laptop computer playing the cartoon SpongeBob SquarePants. On the round table is an iced coffee with a green straw. The second picture in this series shows the profile of Zula, a White woman with brown hair wearing headphones. The third picture shows an image of Zula's legs with her hands on her thighs.

Prioritizing Zula's joy was an essential aspect of our research dynamic. Julia Bascom (2011), an autistic writer and advocate, wrote about the importance of celebrating autistic joy and the legacy of non-autistics limiting autistic expression:

> […] we feel joy—sometimes a joy so intense and private and all-encompassing that it eclipses anything the world might feel. That the world would stop punishing us for our joy, stop grabbing flapping hands and eliminating interests that are not "age-appropriate," stop shaming and gas-lighting us into believing that we are never, and can never be, happy. And that our joy would be valued in and of itself, seen as a necessary and *beautiful* part of our disability, pursued, and shared. (n.p.)

Over the months that we spent together, Zula advocated for her interests, needs, and joy to be prioritized in the research space. Our relationship grew past the initial stages of politeness to include a wider range of emotional expressions, including disappointment, anger, and conflict.

Trailblazers: Inventing an Educational Path

In many ways, Patricia and Zula are trailblazers. On their own, mother and daughter invented a path for Zula's education. Patricia explained, "We're talking twenty-five years ago. There was nothing at the point when she was diagnosed. As she's grown up, we've really been the first wave of different improvements in the field of autism." One of the biggest challenges throughout Zula's school life was the constant changing of schools. In her early school years, Patricia struggled to find a school program that would accept Zula. When Zula entered elementary school, she entered a large urban special education system. Due to the organizational structure of the school system, Zula changed schools almost every 2 years. This meant that Patricia was in a constant cycle of invention and advocacy.

Zula was diagnosed at 18 months with Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS). At the time, PDD-NOS was a subtype of autism spectrum disorder (Gernsbacker, Dawson, & Goldsmith, 2005). In 2013, the DSM-5 collapsed all subtypes of autism under a general autism diagnosis (APA, 2013). Patricia described Zula as an "under-reactive" toddler. For the first few years of Zula's life, she did not have any language. At first, Patricia felt relieved that her baby was extremely calm. Living in a busy city meant there was constant noise, but Zula did not startle in response to the loud sounds of sirens outside: "I was actually happy about that, that she didn't freak out."

Eventually, Patricia became concerned with her daughter's under-responsiveness. She enrolled Zula in a class that involved music and structured interaction with the parent and child.

The experience was a negative one. Patricia struggled to engage Zula and Zula appeared overwhelmed, spending a majority of each class crying or attempting to leave: "She was very difficult to manage." At the conclusion of the class, the director of the class advised Patricia not to enroll Zula in the next series of classes, explaining to Patricia that Zula distracted the other children and was "not a good fit." This would be the first in a series of programs and schools that actively excluded Zula. In this meeting, the director first introduced the idea that Zula had a disability and recommended that Patricia make an appointment with a pediatrician.

After meeting with a pediatrician and a neurologist, Patricia struggled to understand and accept her daughters PDD-NOS diagnosis:

> I think everybody who has a child with autism goes through denial. I had plenty of that. And I thought that what she needed was a little more structure and she needed more time and perhaps she would come out of it.

A large part of Patricia's denial was because she had no model to follow, no older teenager or autistic adult to provide an example to emulate. The advice she received early on came solely from medical professionals who measured Zula's progress against typical child development.

Patricia is a mother of action, so although she inwardly struggled to accept her daughter's diagnosis, she also constantly worked to find the right programs, supports, interventions, doctors, and approaches that would maximize her daughter's growth. In the early years, everything felt hard; Zula did not have language, or an alternative communication system, and thus frequently became overwhelmed and upset. When upset, Zula had large reactions, screaming and crying and responding very little to Patricia's attempts to console her. Patricia described these periods of emotional distress as "tantrums" and explained that during these tantrums, Zula was "difficult to manage." Care routines and errands became challenging: "Nowhere we went could handle her. Shoe stores were horrible. Haircuts were horrible." Extracurricular programs would often request

that Zula not return: “The music class didn’t want her. They didn’t want anyone with a diagnosis.”

Revolving Door of School Placement

With no real model to follow, finding the right school supports and extracurricular activities involved trial and error. Patricia was open to anything she believed supported her daughter: “Sometimes I forget all of the things we did.” The interventions and programs she tried over the years included Applied Behavior Analysis (ABA), auditory processing therapy, music, photography, cooking classes, and Taekwondo. Taekwondo, a form of martial arts, ended up being very fruitful for Zula: “She got to purple belt. The structure was wonderful for her. She did very well there. They didn’t make any exceptions for her, even though she was the only kid with a diagnosis. She did it with the group.” ABA helped Patricia work on potty training with Zula, but otherwise had little effect on Zula’s learning or functioning. Patricia described the total impact of all of these interventions and programs as “cumulative.” None of the interventions or programs stood out to Patricia as specifically important, but their collective impact on Zula was positive. The one constant throughout these different programs and interventions was Patricia’s commitment to her daughter.

For pre-K, Patricia enrolled Zula in a private Catholic school. Patricia was very happy with the pre-K teacher’s flexible and warm approach with Zula, who was not yet using spoken language. Overall, Patricia deemed the pre-K program a success because it was “flexible and there wasn’t a lot of structure.” The expectations for Zula changed drastically when she entered kindergarten, as did the kindergarten teacher’s approach with her. Her kindergarten teacher was “very unpleasant and was looking to get rid of her.” Zula mentioned this school during one of our meetings. I asked her if there was a place in school that she did not like to go and she

responded, “The Catholic school?” She told me she remembered going there when she was 3 years old. When I asked her what she did not like about it, she responded, “It was too hard for me.” Patricia described the kindergarten as a “gatekeeper for the elementary program and they were looking to sort out anyone who didn’t fit the mold, who was not manageable. They wanted to have the kids they wanted.” The exclusion began early in the year; Patricia recalled a Halloween party Zula was not permitted to attend. The event was a school-wide celebration held in the gym where students would visit tables to receive treats. When Patricia pushed the teacher to include Zula, the response was:

> No. If I let her go the other kids will see her behavior, not responding to directions, and that will be a bad message to the other children that this kind of behavior is rewarded, and they can do the same.

After meeting with the principal, Patricia was told Zula would not be permitted to return the next school year. The Catholic school referred Patricia to a special education private school. Zula started the next school year there but was shortly asked to leave that school as well: “It didn’t work out because she was nonverbal then and they did not like that.” This left Zula without a school for several months. Patricia turned to the public school system to request a special education placement.

Patricia and Zula waited from September to February for Zula to be assigned to a public special education program. “For somebody who didn’t have the structure of school or anything else, it was very difficult.” During this time of transition, Patricia and Zula experienced even more stress when Patricia and Zula’s father divorced. This led to Zula and Patricia moving out of their apartment and into Patricia’s parents’ apartment. Patricia slept on a couch in the living room while Zula slept on a bed in her grandfather’s office. As Patricia shared about this period in her daughter’s life, she sighed heavily: “She lost a lot of stuff at that time. She lost her home, she

lost her father, and she loved my parents, but it was a whole different thing." Zula was hyperactive at night and jumped in her bed while attempting to knock the computer off her grandfather's desk. "I really had to hold her down because she was so focused on pushing it off. So that was every night for a long time."

In February, Zula finally entered a special education classroom consisting of five students and two teachers. Patricia was thrilled with the support, specifically their approach to helping Zula acquire language skills. "It was a wonderful little school. They were really teaching them. They would hold a spoon and say, 'What's this?' and she started saying 'spoon spoon.' And it was working for her." She only attended this program for 18 months because she "aged out," meaning she reached an age the program no longer served. Zula changed schools nearly every 2 years. "I forgot all of the schools she went to. Each time it changed, it was a different building with a different bus and bus driver."

One year, Zula was placed in a program with a much higher student-to-teacher ratio than her previous programs. For a number of reasons, Patricia found this classroom was "not appropriate for someone like her." Patricia discovered the program was designed for students with "conduct disorders" versus students with developmental delays, like Zula, with a focus more on behavior management than academic content. "They would say things like 'F you, Mr. Smith. Go to hell.' She was autistic and she was scared. So, she gradually stopped going to class." Zula began spending time in the hallways, refusing to enter her classroom. Patricia got creative and hired Zula's nanny, who cared for her since she was a baby, to be her support person during the school day: "This was actually ahead of its time." But the effects of the nanny's support were short-lived, and after a while, Zula even refused to leave the lobby. "She was regressing out of school all together." After seeing her daughter's resistance and fear towards

school, Patricia advocated for a new class placement and eventually Zula was, again, placed in a different school.

The constant change of school placements, every 18 months to 2 years, defined Zula's school life. The frequent change made developing and maintaining friendships difficult for Zula. When asked about her childhood friends, Zula mentioned a few children:

> I remember Harris, Ethan, Chrissy. Harris my best friend. Yeah. Harris is tall. We had play dates at my house and at Harris's house. After AMAC Saturday program. We baked cookies at my mom's house. We played some activities. I was about five. Daniella. She is a girl. She wore glasses and had dark brown skin. I remember Maggy. Yeah, we [Daniella] used to go to the museum together. Harris, Daniella, my mom and Harris's mom. American Museum of Natural History. I like to look at dinosaur bones.

Zula described activities they did together, going to the museum, or making cookies, but when I asked more follow-up questions, it was difficult for Zula to elaborate. Her memories of peers were fleeting and her descriptions of them indicated that she lost contact with most friends after a year or so. Patricia explained that Harris was a boy from her early childhood and Daniella was a friend from elementary school, but both friendships did not last after Zula changed schools.

I also asked Zula about her memories of students she did not like. At first, she seemed hesitant to describe any peers in this way. When I reframed the question to "Do you remember anyone bothering you?" she was quick to describe a story with Nicholas.

> Z: Yeah, I remember my friend Nicholas. Nicholas was bothering me when I was in elementary school a long time ago in Ms. Margaret's class. Yeah. Yeah…. Nicholas was was…. Let me think…was acting so strangely…. Nicholas was right in front of Ms. Margaret and he wanted to kiss…. And he said I love you….
> R: That must have made you feel….
> Z: Uncomfortable….

A significant contributing factor to Zula's social isolation was the fact that she was often the only girl in her class. In the situation above with Nicholas, she was the target of unwanted attention.

Additionally, her interests in animals, drawing, shopping, and going out to eat were not interests typically shared by her male peers. Patricia explained:

> With boys, they can play basketball, or they can talk about tech, video games, things like that. But if you're a girl and you're not really that into it and you're on the autism spectrum, you really need more social stuff, more interactions. Girls need more. The biggest problem starting from the get-go with girls and autism is that there are fewer of them. In all of the classes she was in, she was pretty much the only girl in the class.

For one year out of her entire school experience, Zula was one of two autistic girls in her class. In addition to being the only other girl in the class, Sarah became her friend. Zula mentioned Sarah's name several times and Patricia described Sarah as her "best friend." The two enjoyed quietly drawing together and generally being in one another's presence, but the relationship did not last because, once again, Zula changed school programs and they lost touch.

Mostly Toxic "Support"

Zula's entry into middle school meant another new program. In this program, Zula joined a classroom of seven other students and was once again the only girl. The transition was difficult for Zula. Not only was she the only girl, but the seven boys had been together since sixth grade. Finding her place in this class was difficult for Zula. When her paraprofessional, Ms. Courtney, began to take an extra interest in Zula, Patricia felt hopeful that the support would help Zula better integrate into the classroom.

Zula has very strong memories of Ms. Courtney. In the 131 pages of transcripts and field notes from my time with Zula, Ms. Courtney's name is mentioned 30 times. The first time Zula mentioned Ms. Courtney was when Zula and I made lists of things she liked and disliked about school. As Zula wrote her lists, I also wrote my own.

Figure 29. *Zula's List*

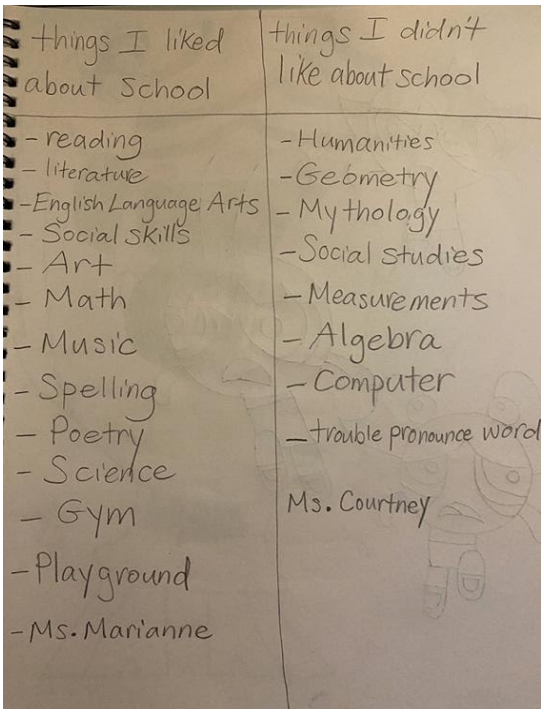
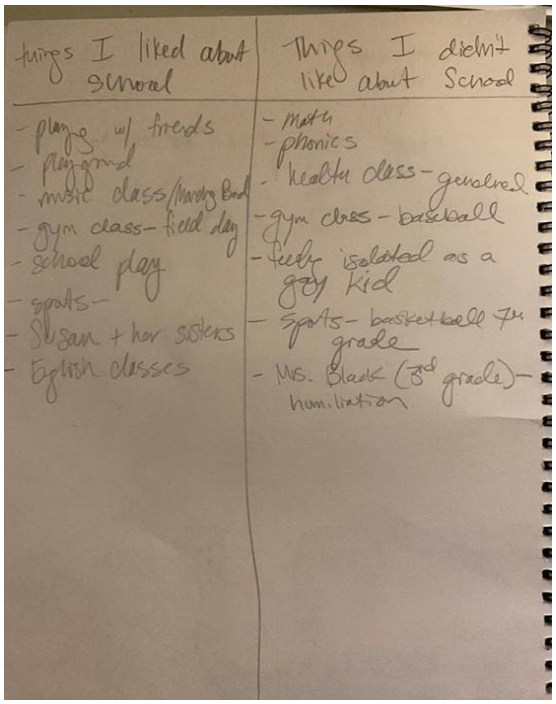


Figure 30. *Rae's List*



What did you like/not like about school?

Zula's "like" list (Figure 29) included reading, literature, English Language Arts, social skills, art, math, music, spelling, poetry, science, gym, playground, Ms. Marianne. Zula's "didn't like" list included humanities, geometry, mythology, social studies, measurements, algebra, computer, trouble pronounce word, Ms. Courtney. Rae's "like" list (Figure 30) included playing with friends, playground, music class/marching band, gym class/field day, school play, sports, Susan and her sisters, English class. Rae's "didn't like" list included math, phonics, health class, gym class (baseball), feeling isolated as a gay kid, sports (basketball in seventh grade), Ms. Black (third grade, when she used humiliation). In the above lists of likes and dislikes about school, "Ms. Courtney" sits squarely at the bottom of the "do not like" column. Zula described Ms. Courtney as having a "temper" and being "not a nice teacher at all."

Z: I did not like Ms. Courtney, yeah.
R: When was she your teacher?
Z: When I was thirteen. In 2007.
R: What was not great about her?
Z: She was kind of acting. Very angry at me. She was yelling and screaming. Acting strangely. She told me I had temper tantrums at school. Really bad.
R: Oh. I wonder why she did that?
Z: She did that on purpose. And (silence)
R: I'm so sorry. That must have been…
Z: It's really not good. It made me uncomfortable. It makes me unhappy.
R: No. Not at all.
Z: Then she called my Mom and Grandma.
R: Hmmmm.
Z: To tell her what I did at school. What was wrong.
R: Hmmmmm. Hmmmmm. How was that for you?
Z: It made me feel upset.
R: Hmmmmm. Do you remember what kind of things made her upset?
Z: Yeah, she made me take away the tickets when I did something wrong.
R: Hmmmmm. Is it ok to talk about this?
Z: Yeah, yeah.
R: So, what happened?
Z: My Grandmother punished me for two weeks.
R: So why did Ms. Courtney take away the tickets?
Z: Because I'm not…I'm not behaving well.
R: That sounds really unfair.
Z: Yeah.
R: Hmmmm. Do you remember what upset you at the time? I know it was a long time ago.
Z: It made me feel uncomfortable.
R: Yeah, yeah. She sounds maybe unkind?
Z: Yeah, yeah.
R: Do you remember the kinds of things at school that would make you feel….
Z: Better?
R: Yeah.
Z: Yeah. I went to camp. NJY camps in the summer. They were good for me. They would make me friends. It would make me feel better. NJY camps in Pennsylvania. And then my mom and Dad would come visit me at camp.

Ms. Courtney's name repeatedly came up when Zula recalled negative school memories. For example, when she was 8 years old, she got into trouble in Ms. Marianne's class. Zula made a connection between these two teachers.

Z: Ms. Marianne was very angry with me. She said I'm not behaving very well when I'm eight years old. She tells me no snacks until you behave properly. Yeah, she yelled at me. I covered my ears.
R: Do you think that was fair?
Z: That was fair.
R: Do you think she's overreacting?
Z: Overreacting. Just like I did in Ms. Courtney's class. She gave me a time-out to sit in the hallway and think about what I did.

Although she had a negative experience with Ms. Marianne, Zula also recalled positive experiences with her. She put her name in the "things I liked about school column" and described her as a "nice woman" who helped her with her spelling (Figure 32). "She teaches me how to spell the word nervous. But I spelled it wrong. Now I spell it like this: N-E-R-V-O-U-S." Ms. Courtney, on the other hand, was consistently described as "mean," "rude," or "not nice." "I never wanted to sit near Ms. Courtney in the cafeteria," Zula explained.

When I asked Patricia about Ms. Courtney, she took a deep breath and spoke in a heavy, hesitating manner: "Ms. Courtney was a high-strung person." Patricia described Ms. Courtney as "working well with boys" and having a personality and style of interaction more suited for boys. With Zula, the only girl, Ms. Courtney appeared critical and seemed to have different expectations for Zula as compared to her male classmates. She constantly critiqued her behavior and her appearance.

> She used to drive me nuts. She was extremely stressful because she would tell me things to do for her. She would tell me I had to get different product for her hair and make-up. Zula was compensating because it was too much pressure on Zula. The underlying message was that Zula was not aesthetically pleasing. She was always trying to push her into something and push her to be more social and outgoing.

Patricia felt both resentful of Ms. Courtney and beholden to her. "It really was bullying. She was a bully. In a way I was bullied by her too. When I was a kid, I was bullied. I think I kind of wanted her to like both of us." Ms. Courtney both criticized Zula and worked to give Zula and Patricia opportunities. For example, Ms. Courtney had a connection to a sleep-away summer

camp and helped Patricia secure a large scholarship to the camp. When Zula described Ms. Courtney above, she mentioned the summer camp at end of the quoted excerpt. I did not get the connection until months later when Patricia explained that it was Ms. Courtney who helped establish the camp connection.

The relationship with Ms. Courtney became increasingly stressful, finally coming to a head at the end-of-the-year celebration. Ms. Courtney planned to take the class out for a nice lunch to celebrate the end of the year. She contacted Patricia and told her to make sure Zula dressed nicely.

> It was a set-up to fail situation. Zula got incredibly, incredibly anxious. Tremendously anxious. And how she manifests it is that she overeats. She told me afterwards how she was eating, grabbing, taking the bread and more bread and more salad. I was devastated. It should've been casual and no expectations.

As Patricia told the story, I could hear the regret in her voice. Later in the conversation, she spoke about parents wanting to protect their children, and I sensed that Patricia regretted not speaking up against Ms. Courtney to protect Zula from her judgment. This woman had bullied both of them.

The constant moving of schools made Zula more vulnerable to this kind of abuse. As the only girl in the class, Zula was easy to single out and hold to different gendered expectations for behavior and aesthetics. Patricia believed that because Zula was often the only girl, and the only autistic girl, she was more vulnerable to this kind of abuse from adults: "Girls are often ignored in conversations around autism. Autistic girls are different than boys. They are more compliant and more social. They just have a totally different experience." Perhaps it was this "compliance" that made Zula more of a target by Ms. Courtney.

Throughout Zula's elementary and middle school years, she was "tracked" in lower academic special education classrooms. *Tracking* is a term used to describe performance-based

ability grouping (Annamma et al. 2016). For years, Patricia felt Zula was "stuck" in classrooms that did not challenge her. In these classrooms, teachers did little to advance Zula's academic growth, thus negatively impacting her access to grade-level material in the next school year. As Zula advanced in school, her limited academic progress contributed to teachers setting lower academic expectations of her, which further exacerbated her academic growth, thus ensuring her place in the "lower academic track."

In high school, Zula met Ms. Theresa who helped Zula break the pattern of low expectations and limited academic growth by helping Patricia place Zula in a "higher academic tracked class." As Patricia explained it, Ms. Theresa "gave her a chance." For Zula, this meant that rather than remaining in a special education class, housed inside a high school, Zula joined a hybrid job-skills class located on the campus of a local college. The class operated out of the college mailroom, and the curriculum focused primarily on mailroom job skills. Zula enjoyed the job immensely and became skilled at sorting and delivering mail around campus. The job allowed Zula the chance to have responsibility and to navigate social interactions in the workplace. Zula described the job fondly and mentioned it several times over the course of our meetings. Patricia appreciated Zula's teacher who "was nurturing but had high expectations for Zula." The mailroom job ended when Zula graduated from high school.

For Zula to be successful, her mother had to advocate for her at every turn, constantly pushing for just the right program. Patricia knew that her daughter needed a small classroom, with peers who did not overwhelm Zula. She also knew Zula was capable of academic achievement. Patricia continued to advocate for a balance of support and high expectations throughout Zula's entire school life.

Interdependence in Adulthood: Connection and Community

Graduating from school-based programs can be a very difficult transition for many autistics. As I discussed in Chapter I the period after high school is commonly referred to by parents and autistic advocates as "falling off the cliff," due to the drastic changes in funding and access to supports (Hanley-Maxwell et al., 1995). Many autistic young adults struggle to find meaningful employment, stable housing, and community connections outside of the organizational structure of schooling (Newman et al., 2011; U.S. Department of Health and Human Services, 2017).

For Zula, however, her transition out of school and into young adulthood provided her with new possibilities and an increase in connection, community, and choice. With Patricia's support, advocacy, and guidance, mother and daughter built an independent/interdependent adult life for Zula. Disability studies scholars and activists have long troubled the myth of "independence" as the goal of successful adulthood and argued that no one can thrive completely on their own (Kittay, 2011; Mingus, 2017). Instead, independence should be reframed to include notions of agency. As disability rights pioneer Judy Heumann (1978) explained, "To us, independence does not mean doing things physically alone. It means being able to make independent decisions" (cited in Stoddard, 1978, p. 2). Interdependence, mutual and collective support, moves away from individualism and "towards relationships where we are valued and have things to offer" (Mingus, 2017, n.p.). In adulthood, Zula found a devoted partner, secure housing, hobbies, and meaningful employment. Most recently, Zula joined a community of other autistic women and, for the first time in her life, she has female autistic friendships.

After graduation, Patricia focused her energy on helping Zula find meaningful work. She knew Zula thrived with structure and routine, and she wanted to build on the success of Zula's high school experience working in the mailroom.

> I just want her to work. I needed her to be occupied and out of the house. She started volunteering and now she works at this thrift shop. She makes thirty dollars a week. She likes the manager. It's very meaningful for her. She ends up working about four days a week. The job is very important to her.

Zula's salary of $30 a week is very low, and although Patricia did not go into specifics, receiving an income from an employer can complicate benefits for disabled people. If Zula's thrift shop job exceeds the amount of money she is allowed to make per month, she will lose her federal and state disability benefits (Newman et al., 2011). For Patricia, the important aspect of employment for her daughter was to have a sense of purpose, routine, and connection with others.

Zula takes great pride in her work at the thrift store and has been employed there for several years. Work is a big part of her weekday routine. I will often get a text from Zula that reads "Tomorrow I will work at the thrift shop" or "Today I had a good day at the thrift shop!" She explained her job duties to me:

> I like to work at the thrift shop all of the time. I like to sort the clothes and to sort the price tags. Fixing the jewelry and sweep the floors. I like to make some signs and, also, I greet the customers in the polite way.

Zula spoke highly of her manager and coworkers. She enjoys making her own choices on how and where to spend her salary.

Love, Partnership, and a Shared Home

During school, Zula had inconsistent friendships and often lost touch with peers after transitioning to a new school program. In adulthood, one of her most significant relationships has been with her husband, Ben. Ben and Zula have been married for 3 years and live together in an apartment not far from Patricia. Zula described Ben as "very handsome" and was quick to pull

out her phone to show me a selfie of the two of them together. They enjoy household routines like cooking, grocery shopping, watching TV (they enjoy *The Bachelor*), cleaning the house, going to the movies, and going out to dinner. Every Friday night, Ben and Zula meet Patricia and her grandfather at their favorite Italian restaurant. Each day after work, Zula walks four short blocks from the thrift shop to her mother's apartment where she watches TV and spends time with her four cats. Then at 6 o'clock each evening, Ben walks to Patricia's apartment to pick Zula up so that they can eat dinner either at a favorite restaurant or at home. On Thanksgiving, Ben's and Zula's families often get together for a big family celebration.

It is very clear that Zula and Ben have a strong connection. Several times during our research meetings, Ben called to check in with Zula: one time calling to schedule their flu shots, another time calling to inquire after Zula's dinner preferences—"Oh, it's Ben calling." Zula answered the phone with a smile. "Hello Ben. Yes. Halal cart? Yes…chicken and salad…. No rice. I'm on my Weight Watchers." On a few occasions, I met Ben via Facetime. Each time, Ben and Zula were seated closely together on the couch in Patricia's apartment, watching the evening news with a cat snuggled up on each of their laps. Zula described Ben as "the best cat person. He likes Sylvester the best."

Patricia introduced Ben and Zula. Patricia met Ben through her job at the hospital where Ben works in the transportation department. Ben reminded Patricia of Zula: "I always thought he was autistic, but I later learned he was schizophrenic, but always took his meds and was a really sweet guy." One day, Patricia asked Ben if she wanted to meet her daughter. He responded, "Do you know I'm forty?" Patricia was surprised by the 15-year age gap but took down Ben's number regardless. Ben and Zula met for pizza and got along well; they began to spend time together regularly.

When they first started dating, Ben lived with his grandmother. After his grandmother passed away, he took over the lease of the apartment. When Ben struggled to live alone, his family began looking for more of a support network. Patricia spoke to Ben first and then approached Zula. “At that point, Zula and Ben were spending so much time together. I trusted that Ben would never hurt Zula. I thought this was an opportunity for them to live together as roommates in a friendship capacity and that it would be good for Zula to live apart from me and not be so dependent on me.” Patricia was eager for Zula’s networks to extend beyond their close mother-daughter bond.

Zula and Ben created a happy routine together, and over time, their relationship evolved. Patricia described how they have clearly defined roles and routines: “They do their laundry together. He washes. She folds. They cook together. They go out to eat together. After a while, she came to me and told me they wanted to get married.” Patricia was supportive and felt excited to plan the wedding, but Ben’s family felt worried. For Ben and Zula, a legal marriage involved each of them losing a significant amount of their disability benefit.

For this reason, Patricia stopped the wedding planning. “They both were terribly disappointed, and it made me realize how serious they were about it that they really wanted to have a ceremony. I thought it was great.” Foregoing a legal wedding, Patricia, Zula, and Ben forged ahead with planning a wedding ceremony. They held the ceremony at their favorite Italian restaurant. Zula wore a navy-blue gown and a small tiara perched on top of her professionally styled hair. A captain served as the ceremony officiant. “He was amazing and had a serious talk with the two of them before the ceremony about the meaning of commitment.” The two exchanged rings. Zula’s ring is a beautiful diamond ring that belonged to her grandmother. As

Patricia recalled the story of Zula's wedding, her voice filled with pride: "It shows you how far Zula has come."

With each step into adulthood, Zula and Patricia's relationship shifted. When Zula was a child and teen, Patricia always knew exactly what Zula was doing: "Her world was my world." Growing up, Zula did not have much of a social life outside of school, and on the few occasions when she did spend time with school friends on weekends, Patricia or Zula's grandmother was always present. Patricia and Zula were rarely apart. As Zula became an adult, Patricia embraced the changes in their relationship and understood that Zula needed space to make her own choices and, potentially, her own mistakes.

> When the rules change, when things change and the child is growing up and has different experiences, you're not there with them. And you hope for the best, but you can't not let them go. They come back hopefully better, not traumatized.

It is striking that Patricia was able to make this transition in her role as the parent advocate. As a parent to a school-aged child, Patricia was constantly in protection mode, helping Zula navigate her new schools and classes and advocating for her. But as the mother of an adult, her advocacy looks different. Patricia wants her daughter to have a life apart from her own, with new networks of support.

Autistic Women and Community

Throughout her school life, Zula was nearly always the only girl in her class. She had very limited experience with autistic female friendships. When Patricia heard about Phoebe's Place, an organization designed for adult autistic women, she was thrilled. Phoebe's Place is an organization that provides space and programming for adult autistic women to socialize and share their hobbies and interests. It is also a community of shared resources, where members help support one another through job interviews, asking for accommodations, or navigating a

difficult relationship. Phoebe's Place is an incredible organization run by and for autistic women. There are no goals, no therapists, and no facilitators, and it is free to attend. Patricia attempted to enroll Zula as a community member a few years ago, but during the interview process, Zula became nervous and shut down. The organization was reluctant to include Zula in their programming, concerned that she would get lost without any facilitation.

Patricia was disappointed that Zula missed the opportunity to participate in the Phoebe Place community. Outside of her relationship with Ben, Zula's friendships are somewhat limited: "She doesn't have a large network of social interactions. This would be so good for her." The opportunity to revisit Phoebe's Place came during the holiday season. Through my professional networks, I was invited to an open-house holiday celebration, and I invited Patricia and Zula to attend the event with me.

Patricia, Zula, and I met at the event space; both mother and daughter wore festive sparkly holiday sweaters. When we arrived, we quickly found seats in the beautiful auditorium. The opening act was a jazz quartet that played holiday songs. The musicians were college students from an elite music conservatory, and they were gifted performers—a few songs into the playlist and the crowd were clearly hooked. I looked around the auditorium and saw 50 autistic women stimming, dancing, rocking, and smiling, joyfully immersed in the holiday music. As guests arrived, the event organizers passed out fidget toys, small marbles, and spinning tops for people to fidget with during the performance. Phoebe's Place community members wore white buttons identifying themselves along with colored stickers. Each sticker signaled a type of interaction style they preferred. A red sticker meant the individual was not interested in small talk and a green one indicated that a person was looking to find a new friend. Zula smiled and rubbed her legs as she rocked perfectly in time with the rhythm of the music.

Patricia tapped her foot and mouthed the words to herself. At one point, daughter and mother held hands and swayed in their seats. This was the first time that Zula was immersed in a community of other autistic women, a community of autistic joy.

At the event, Zula and Patricia met the director of Phoebe Place. The week after the holiday event, Zula went for another interview. Several weeks later, I received a text from Patricia: "Zula was accepted into the program and she's already joined an art club!" Months later when the pandemic shut down many of Zula's social outlets, Phoebe's Place continued to hold art classes and groups online. These art classes and online community meetings became very meaningful to Zula, a place of connection.

AFTERWORD: "Please walk me home"

"I'll have the pad Thai with shrimp please."

"Should we split some spring rolls?"

"Oh, sure, Rae! I'll have the Thai iced tea, please."

Zula and I sit silently at a small table in the corner of the Thai restaurant. Beautiful lights hang from the ceiling, setting a beautiful warm glow across the tables. After we order our food, we sit quietly waiting for the waitress to return. For a moment, I feel compelled to ask Zula a question, to fill the silence. "How's Ben?" I start to say, but then I catch myself. What if I…… don't? Don't fill the silence. Embrace the quiet intimacy. Zula smiles and hums to herself as the food arrives. It's delicious. She looks up a few times and catches my eye and shoots me a grin of delight. We share the silence together for an hour, communicating our comfort through gestures, glances, and space.

After dinner, we walk the three blocks to Phoebe's Place. They are hosting a community event, a panel discussion with the Board of Directors, a group made up entirely of autistic women who are activists and scholars. The women share their experiences and speak on the reality and challenges of being an autistic woman. At one point, one of the participants leads the crowd to collectively sing Alicia Keys' "This Girl Is on Fire." Zula immediately joins in and loudly sings the lyrics along with the auditorium of autistic community members. Her arms wave in unison with the other women as they hit the high note, "FIIIIIIIIRRRRRREEEE! THIS GIRL IS ON FIIIIRRRRREEEEE." As the event ends, Zula loudly calls across the room to some friends she knows from her cartoon drawing art group. "Hi, Julia. It's Margie!!! Hi! I know you, Beth!"

We walk out of the venue and find that it's raining. "Please walk me home," Zula requests. Her tone suggests it's less of a question and more of a statement. The venue is across town from her apartment but is right next to the train I need to take home.

And so, I ask her, "Can I walk you halfway to your mom's apartment?" Zula responds with a smile. "No, all the way to my apartment with Ben." And so, we walk the 20 blocks to her apartment together, swiftly and silently.

FOREWORD TO CHAPTER VI

The photograph below shows the hands and feet of Jordyn, a Black woman who is holding a picture. Her feet are tucked under her body. She is wearing a green sweater, black stretch pants, and white socks. She is seated on the floor on top of a braided multicolored rug. Around her are several pages of collaged pictures that Jordyn has created from photocopied pictures of her old middle school yearbook. The individual pictures of students are attached to the white paper with emoji stickers.

Figure 31. *Jordyn*

Jordyn is a 26-year-old Black, autistic woman with short black hair. She frequently wears an oversized green turtleneck sweater and black leggings. Jordyn communicates with short phrases and gestures. She has an extremely warm smile and a good sense of humor. Jordyn's mother, Ada, described her daughter as someone who is an excellent judge of character and possesses a deep sense of compassion for others: "I think she has a lovely spirit." When Jordyn is comfortable, she will often show affection by holding onto the arm or elbow of a trusted person.

I first met Jordyn when she was a teenager. She attended the school Oakwood Academy, where I worked for many years as a teacher and later as a staff trainer. After nearly a decade since Jordyn left Oakwood Academy, I ran into Jordyn's mother, Ada, at an academic talk given by a researcher who examines the particular experiences of autistic girls. When I looked across the academic lecture hall and made eye contact with Ada, we both smiled broadly in recognition. Jordyn had never been a student of mine, but I was familiar with Jordyn and knew her parents from various school events. Jordyn's mother, Ada, is someone one does not forget. She is warm, charming, accomplished, and a wonderful advocate for Jordyn. She is the kind of person who, after not seeing someone for years, greets that person with a warm hug and immediately says, "I'm so happy to see you!"

When Ada learned about my study, she was eager to speak to Jordyn about being involved as a participant: "It's very good you're doing this topic. Girls just don't get enough attention," she told me. Later, when I explained that the project was a narrative inquiry study, Ada was excited: "I think she's got stories to tell and I would like to hear them. I'm trying to figure out a way to help her do that." A few days later, I received a confirmation from Ada that Jordyn was enthusiastic about participating in my project and expected a visit from me at their family home. In our first meeting together, Jordyn greeted me with my full name: "Hello Rae

Leeper." Ada smiled and added, "I bet she's been googling you. She's been excited that you're coming."

Similar to Zula's chapter, Jordyn's narrative is co-constructed with Jordyn, her mother, and me; however, Jordyn's mother, Ada, is more present in this chapter. Jordyn communicates in short sentences and through pictures. I share her collage creations and vignettes from our research together to privilege her own storytelling and her mode of expression. Ada, however, is the narrator for the majority of her daughter's school experience. Disability Studies understands the important and intimate role that parents play in sharing their children's stories. Parents do not *speak for* their disabled children but instead *speak with* their children by interpreting and sharing both the perspectives of their children and their own parent narrative (Adams, 2013; Alper, 2017; Berube, 1996; Ferguson, 2001; Kittay, 2019; Rapp & Ginsberg, 2011).

My previous relationship with Jordyn and her family via Oakdale Academy also makes this chapter different from the others. This relationship gave me a sense of intimacy and comfort with the family and some insider information regarding various aspects of Oakdale Academy. Because I no longer work at the school and because Jordyn has not attended the school in years, I do not see this as a conflict of interest, nor do I believe that researchers are neutral (Kim, 2016). Instead, when I describe Oakdale, I am careful to privilege Jordyn's and Ada's perspectives. Ultimately, I understand our shared experience at Oakdale as helpful for our relationship building.

Jordyn lives at home with her older brother, Brandon; her mother, Ada; and her father, Joel. The family is very close. They live in a Victorian-style house with a large front porch; inside, the walls are beautifully decorated with framed artwork and family photos. Joel and Ada are both highly successful in their respective careers. Ada works in marketing and at one point

ran her own firm. Combining her personal experience with advocating for her autistic children (Brandon is also autistic) and her professional experience in marketing, she now works for an autism-related research firm. Joel has an MBA and works in investment. Joel's father was a Tuskegee airman, one of the first Black military pilots in the US Army Air Corps (Moye, 2010).

Jordyn and her brother Brandon, both autistic, are very different and have different support needs. Jordyn communicates in short sentences, she attended private special education programs, and all of her classmates were students with disabilities. After graduating from a special education high school, Jordyn began attending a day program designed for adults with disabilities. A bus from the adult program picks her up and drops her off at her house each day. In the community, Jordyn receives support from a parent or another support person to run errands in her neighborhood. She especially enjoys going to the local dollar store to retrieve art supplies and journals or to the grocery store. Jordyn's brother, Brandon, is a highly verbal 30-year-old autistic man who, after graduating from high school, attended college. Brandon is now employed as an administrative assistant in a doctor's office. He enjoys taking public transit to work and does so independently.

Over the course of 6 months, I met with Jordyn 13 times for approximately 18 hours. Most of the research meetings took place in their family home, and my time spent with Jordyn was generally spent in her bedroom. During my meetings with Jordyn, I took photographs, audio recordings, video recordings, and field notes. Each time I visited, I talked with Ada. I conducted a more structured interview with Ada halfway into the research study to learn more about Jordyn's specific school supports and diagnostic history. The interview occurred at her kitchen table and Jordyn was present for the majority of the meeting. Jordyn and I usually met on Thursday evenings at 6 p.m. This time worked best for Jordyn and her family. Jordyn arrived

home from her day program around 4 p.m., ate a snack, and napped. She was often still asleep when I arrived.

Although Jordyn typically speaks in short phrases, during some of our meetings, she preferred not to speak at all. Our meetings were spent listening to pop music, playing Candyland on her bed, sitting on the floor cutting out old yearbook pictures, creating collages, or simply sitting together as Jordyn played on her phone or looked at YouTube. A typical conversation between Jordyn and I usually revolved around these research activities.

R: I brought a yearbook today.
J: Oakwood Academy 2010.
R: Yes, you're right.
J: Glitter glue?
R: I bought more this week since we ran out last time.
J: Purple one. Scissors please Rae.
R: Do you want to use the glue stick as well?
J: No thank you.

Jordyn also initiated questions regarding schedules or upcoming events: "Rae will come on November 5th at 6 p.m." On one occasion, I accompanied Jordyn, Ada, and Brandon on their weekly grocery shopping trip, a favorite destination of Jordyn's.

Learning to understand Jordyn's communication took time and required building a relationship. As Disability Studies scholar Ferguson (2001) explained, "reading" his disabled son, Ian, required a relational stance, a sense of intimacy, and a deep belief that his son was communicating something even in "the wink of an eye" (p. 145). Jordyn shared with me her perspectives though a smirk, a twinkle in her eye, a hum, a repeated phrase from a song or a YouTube video, a particular collection of photographs or stuffed animals, or pictures sent to me via text message. Jordyn's gestural communication also held meaning. Melanie Yergeau (2018) argued that telling autistic stories is a radical act as autistic people have been de-storied and

constructed as non-rhetorical and involuntary; “in all things discursive, autism represents a decided lack” (p. 7).

Similar to Chapter V, I employ the use of descriptive self-reflexive vignettes (Lutrell, 2010) to make transparent my research choices as well as the way I interpreted Jordyn’s communication. I use many photographs within this chapter. Jordyn has a strong visual sense; therefore, telling her narrative through photographs is a way that I privilege her individual sense making and storytelling. Rather than try to interpret their *meaning*, I share her images as a way to share her *perspective*. I share my interpretation of these images, why I chose them, and what I think the reader can learn about Jordyn through these images in the caption titles and the image descriptions.

Chapter VI: JORDYN

This chapter is presented in two sections. The first section is devoted to Jordyn in the research space and explores the ways that she communicated through art-making activities (picture collage), movements, words, and affective exchanges. The second section explores Jordyn's school history as well as her transition out of school and into adult support services. This second section is told from Ada's perspective. I have incorporated various yearbook collages throughout her school story to highlight Jordyn's perspective. Because these collages include photographs of other students, they are presented in a way that obscures the identities of other students. I either digitally added emojis to obscure student identities or kept the images small or blurry.

Communicating with Jordyn

Over the course of the 6 months that Jordyn and I met together, I became more and more familiar with her preferred communication patterns. I started to pay more attention to what textures she gravitated towards, what music she preferred, where she liked to sit in the room, and how she organized objects in her space. Over time, the focus of my research meetings with Jordyn shifted from thinking about my research questions to thinking about Jordyn's access needs. How does she feel most comfortable? How can she most comfortably express herself? In what space does she feel the most at ease? How many questions are too many questions? I found that the more I prioritized Jordyn's joy, interests, comfort, and communication preferences, the more I learned about her.

Research meetings with Jordyn felt awkward initially. We held our first meeting in the family kitchen. Jordyn had set up a game of Candyland at the kitchen table and seemed eager to

play when I arrived. Two minutes into the game, however, Jordyn got up and wandered out of the room. Ada, who was in the kitchen cooking, followed Jordyn and cajoled her back to the kitchen table: "Come on, you agreed to do this research with Rae. Come back." I felt concerned that Jordyn would see me as a kind of "work" or "obligation" and was unsure how to shift to that expectation. Although I assured Ada that I was absolutely happy to sit and take time for Jordyn to feel comfortable, I believe Ada was sensitive to my time and worried that I was not getting what I needed from the meetings. The meeting ended with Jordyn saying, "October 18th play Candyland with Rae," which I took as a good sign that she was still interested in collaborating. The following visit, when Jordyn again wandered away from the kitchen table, I asked her to show me her favorite space in the house. With both Jordyn's and Ada's permission, I followed Jordyn upstairs to her bedroom.

Candyland Improv: Playing by Different Rules

Jordyn's room is her favorite place. When I walk into her room, I see that it is brightly lit with a large comfortable white four-poster bed. The walls are covered with beautifully framed prints of famous Black artists. Her bookshelves are filled with children's books. Nestled on top of her desk, the top of bookshelves, and peeking out of drawers are photographs. Several photo albums are strewn across Jordyn's bed. The photo albums contain pictures of a young Jordyn, 6 or 7 years old, on a family trip with Ada, Joel, and Brandon. In addition to these albums, there are individual photos tucked among items around her room, including a class picture from her first grade classroom, and several photocopied yearbook pages showing various class trips. The year on the page read "Oakdale Academy 2006." There is an additional page with small pictures of students cut out from the yearbook on which Jordyn has written descriptions. Each of

the pictures shows a student dressed up for Halloween; some of her written descriptions read, "Elijah wears a wig. Elizabeth wears a yellow costume" (Figure 36)*. Each of these pictures is at least 10 years old. Because I worked at this same school, I also knew that these particular students were much younger than Jordyn and did not share a classroom with her. Why did she choose these specific students' pictures?*

Jordyn organized items in her room in a particular way. Large baskets of stuffed animals lined her walls (Figure 32)*. Tucked among these stuffed animals are more photographs from old yearbooks. Around her room, Jordyn has categorized other items into single plastic bags. These items include a bag of colored markers* (Figure 33)*, a bag of Cheerios, a bag of chocolate Snowcaps, and a bag of M&Ms. Her bookshelf is lined with six or seven bottles of Polar seltzer, all half empty and placed in a neat row. Her preferred flavor appears to be orange vanilla.*

Immediately upon entering the room, Jordyn hops on top of her bed and pulls a thick quilt up over her legs. She smiles at me, clears her throat, and takes out her phone and begins looking up clips on YouTube. I feel a shift in her comfort level as compared to our previous meetings in the kitchen. She seems to settle into the space. I was not getting the same sense of restlessness that I had during our kitchen meetings.

In preparation for this meeting, I photocopied an old yearbook from Oakdale Academy and put it in a three-ring binder. I notice individual pages and pictures from that same yearbook around Jordyn's room. I am excited to show her the photocopies and have brought markers, glue, and scissors along, thinking she will enjoy cutting out the images and creating a collage. I am not sure how to "get started." Where do I sit? Is it ok to sit on her bed? Is that too intimate? Is that invading her space? Do I sit on the floor? If I sit on the floor, then I'm several feet away

which feels awkward. I am so curious to see what she is doing on her phone. I hear 10 seconds of a Taylor Swift song (from the older Country era), followed by a quick 10 seconds of the movie Space Jam *(Pytka, 1996) with Michael Jordan and various cartoon characters, and then 10 seconds of an Ella Fitzgerald song. The effect is dizzying with the speed at which she changes course, but there is also something creative about her choices, almost like she's a DJ making a mix of seemingly unrelated beats. In each of these juxtapositions, there is a new meaning.*

I stand frozen for a while at the foot of her bed, holding the yearbook. I have no idea what to do next. Then I spot the Candyland game on her desk. Ok. Maybe this is a way in. I set up the game at the end of her bed and bring a chair over to sit. She does not look up at all, still looking at her phone. I sit for another 10 minutes, but it seems like an eternity. What am I doing? Am I being offensive just sitting here watching her? But then again, I do not want to make her feel pressured to do something she is not interested in doing. Suddenly she looks up, puts down her phone, and says, "Rae let's play Candyland." She spots the photocopied yearbook on the floor and grabs it and smiles, "Oakdale Academy 2006." For the next 20 minutes, there is a flurry of activity. Jordyn switches back and forth between flipping through the yearbook, moving the pieces of the Candyland game, and going back to her quick YouTube searches. At one point, she plays a section of an improvisational jazz singer. The horns and drums are wild and unpredictable. I remember Ada mentioning that Jordyn had an interest in complicated jazz music.

During this meeting, I am introduced to Jordyn's style of Candyland. During our earlier meeting, we only completed a few turns in the kitchen before Jordyn left the game, so I did not know that when Jordyn truly plays Candyland, there is no beginning or end to the game. There

are no winners or losers. Instead, the game consists of a complicated series of circuits. She starts this game by assigning me a color and a figurine—"Rae you have the blue girl. Jordyn has the yellow girl"—but three turns into the game and she is moving my piece and I am moving hers. At first, I think, "Oh, she's cheating" but then I recalibrate: "Nope, she's just playing by different rules." She searches through the stack of Candyland cards to find a desired card: "double yellow" she says, but then she gives me the card. Our pieces move wildly across the board. When one of us gets to the end, rather than "win," she simply starts that piece back at the beginning. Jordyn's Candyland game resembles the unpredictable and creative gestures of jazz. At first, I am uncomfortable. I have no idea how to participate. What are the rules? Then I let go of my expectations, and Jordyn and I begin to develop a flow to the game. She takes a few turns, then I feel a natural pause in the flow and step in to take a few turns. Then she grabs a card, and this is my cue that my turn is over. A particular meter and rhythm emerge between us. We both smile and occasionally catch one another's eye.

A few minutes into the game, Jordyn takes a break and begins to look at the yearbook. She studies particular pages and I take note of them. As she looks at the pages, she smiles, presses her thumb under her two front teeth, and hums. What is she thinking about? Is she returning to a particular memory? Is there something about this student? This field trip? I notice that the pages she lingers on do not include pictures of herself or her class from that year. At one point, she opens the three-ring binder and takes out three pages from the yearbook and places them on her bed. Why those pages? She returns to Candyland and our game continues.

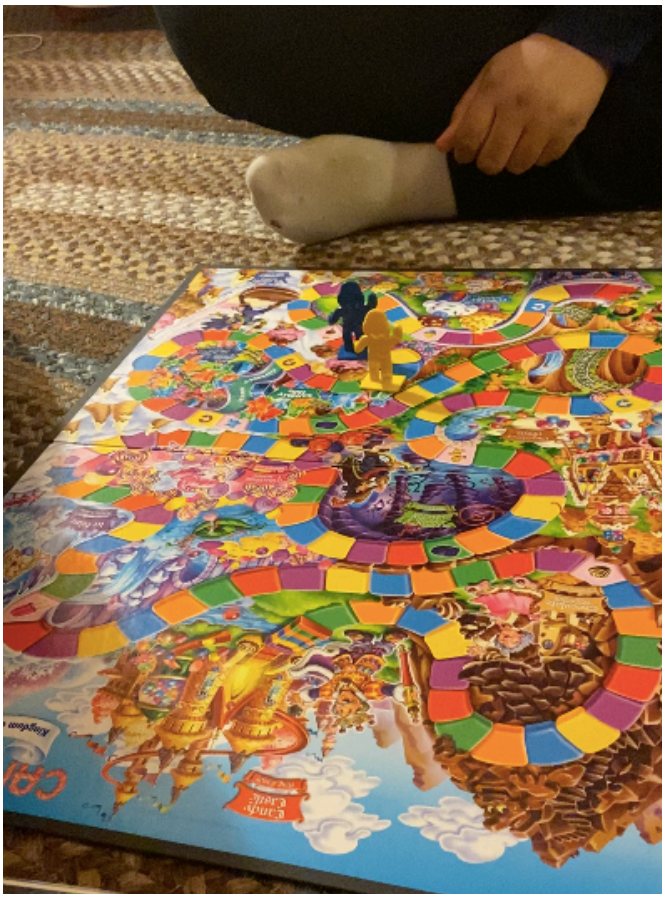
About an hour into the meeting, Jordyn gets up and says, "Time to eat," and leaves her room. I assume she is heading down to the kitchen for dinner. I start to pack up my belongings,

the yearbook, the pages on her bed, and the art materials. I put away the Candyland game and return it to her desk. I am putting on my coat when she comes back into the room eating a sandwich. She looks surprised to see me wearing my coat. "Rae stay and play Candyland?" she asks. At this point, it is getting late, so I tell her it is probably time for me to go, but I would see her next week. "Where are the pages?" she asks me. I am not sure what she is talking about and then I realize she is referring to the pages she selected from the yearbook. I had put them in my bag with the intention to scan them, but immediately realized I should have asked her first. I felt embarrassed that I had crossed this boundary with her work and made a mental note to ask her in our next session if I could take a picture of the collage. "I'm sorry. I should have asked," I say. Jordyn retrieves the pages from my bag and places them on a stack and then smiles at me as she confirms our next meeting. "See you on October 28th Rae." I leave our meeting, feeling good about the connection that I felt today, but unsure of where to go next.

Figure 32. *Everything In….*

Figure 33. *…Its Right Place*

Figure 34. *Rae Is Blue Girl. Jordyn Is Yellow Girl*



The above photographs were taken in Jordyn's bedroom from our research meetings. Figure 32 is a photograph of three baskets of stuffed animals, including a dog, a large crab, a monkey, and the Grinch, and they show the way Jordyn has organized and sorted these items. The largest stuffed animals all share the largest basket, and the smallest basket contains all stuffed dogs. Figure 33 is a photograph of a plastic bag filled with markers. Jordyn would organize similar objects together in plastic bags, including cereal, chocolate, and various art supplies.

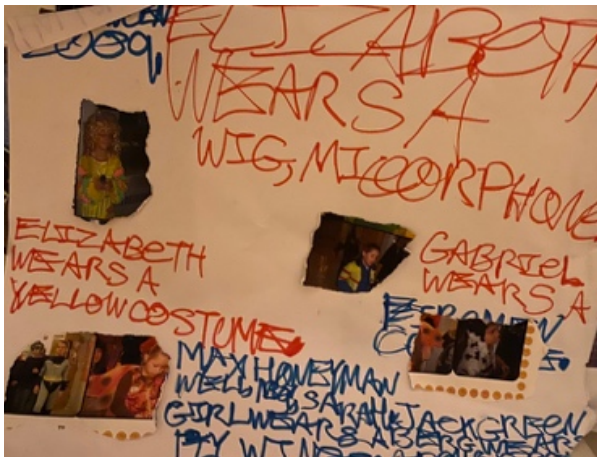
Each of these photographs shows the great care that Jordyn takes towards objects in her space and the importance she places on a particular sense of order. During our sessions, Jordyn

would often get up from what we were doing, go to her desk, and select one particular piece of paper or a photograph from the middle of a stack of papers. She possesses a deep intimacy with the objects in her bedroom and has an internalized sense of exactly where items are placed. Jordyn appeared to take great pleasure in returning items to the exact place in which they were intended, an order that was very specific to her own sense of their use, their size, their color, and their meaning. Autistic writer and activist Max Sparrow (2016) described that "autistic happiness" is linked with a sense of order; "happiness is when everything is arranged by color and size. Happiness is when the last number fits and the puzzle is perfect" (n.p.).

Figure 34 shows Jordyn seated on the floor with a Candyland board in front of her. To begin each session of Candyland, Jordyn would assign roles. Candyland proved to be a huge turning point for me as a researcher. When I began to realize my own rigidity and discomfort with not knowing *the rules* of her game, I began to understand how I had to let go of preconceived notions of what our time together would look like and instead pay more careful attention to the cues that Jordyn was already telling me.

Figure 35. *And the Sound of Children's Laughter Fills the Air*

Figure 36. *Elizabeth Wears A Wig, Elizabeth Wears a Yellow Costume*



Figures 35 and 36 show pages from an old Oakdale Academy yearbook, the school Jordyn attended in middle school and where I also worked for many years. These two pages were present in her room before we began our photo collaging and were the inspiration for our collage project. Figure 35 shows several images of children swimming in a pool. Jordyn sought out this image often. During one research session, she took out her phone and began playing the Maria Carey song, "All I Want for Christmas Is You." She showed a particular interest in a lyric of the song, "and the sound of children's laughter in the air." Jordyn repeatedly rewound the song and replayed that particular lyric over and over as she looked at the photograph and smiled. I understood this to be a way that she narrated the children's joy in the photograph and perhaps her own joy in seeing their happiness. Similarly, Figure 36 shows children joyfully engaged in dress up for Halloween at Oakdale Academy. Jordyn created this collage before we started our research together and this image served as an inspiration for what our time together could involve. Jordyn wrote some words to describe each picture such as "Elizabeth wears a wig." Several times throughout our research meetings, Jordyn would make mention of particular students and their Halloween costumes, both from Oakdale and even as far back as her elementary school. Similar to the pool photograph, I believe she was attracted to the children's joy and sense of celebration.

Attempting to Guide the Research Agenda: "No Thank You" to "More Please"

Over the next several months, Jordyn and I continued to spend our meetings working on collages from yearbooks, playing Candyland, and listening to YouTube. In the first month, I felt pressured to focus on the task of interpretation. What did these collages mean? Why did she pick these particular images of students? Why was she not featured in most of the collages she

created? Each week I tried a different way to better understand her meaning making and to allow for multiple ways for her to express herself.

The first way I approached this was to make note of which pages she lingered on the longest. Then in the following meeting, I brought multiple copies of those pages. Some were intact and some I cut out in advance and carefully sorted the pictures in small baggies (Figure 37). I thought the plastic bag sorting might appeal to her aesthetically because of her own organizational system. I brought a sketch book and various art materials, including a purple pencil sharpener that Jordyn specifically requested.

When I presented Jordyn with the preselected images, she was not interested. Instead, she returned to the large three-ring binder, flipped through the pages, and selected an additional page—a page showing a bunch of children on a field trip to a children's museum. She cut out each individual child's photo and pasted them onto a blank piece of paper that she had ripped out of the sketchbook. She took great pleasure in applying the glue, especially the glitter glue, with a pointed tip. As she applied the glue, she made quick circular patterns and covered the back of the image completely before applying it to the blank sketch pad. She hummed and rocked back and forth slightly as she made the circular motion with the glue. The experience of collaging was a full-body experience. She would rub the excess glue between her fingers and occasionally smelled it. I offered Jordyn markers and colored pencils, thinking she might want to write on her collage, but her response was, "No thank you." Instead, she took a few colored pencils out of the box, broke the tips off three of them, and then resharpened them with the purple pencil sharpener.

In the following few meetings, I made other attempts to explore her school memories. On one occasion, I made a T chart, similar to the chart I had made with Zula. I wanted to know more

about how she felt about these past relationships. At the top of the chart, I wrote, “Teachers I Liked” and “Teachers I Did Not Like.” I made a similar chart for places in the school and students in her class. I went through the yearbook and made extra copies of spaces in the school, teachers, and classmates. When I suggested the sorting activity to Jordyn, she said, “No thank you”; she then flipped the T chart over and began freestyle collaging on the back. In another meeting, I prepared prompts including “I like to play _____. I really liked this teacher _____.” I thought because she enjoyed list making, she may enjoy filling in the blanks with either an image or writing a name. Instead, she proceeded to paste images onto the page in her own way. Jorden kept each of the collages she created, but allowed me to take a picture of each collage before she neatly tucked them away in a stack of papers on her desk.

Figure 37. *Picture of Research Activity Supplies in Presorted Bags*

Figure 38. *Research Sketch Book My Question Prompts*

Figures 37 and 38 show various stages of our research process together. Figure 37 shows the ways that I attempted to organize the materials. By paying attention to the way that Jordyn had organized her markers into individual plastic bags (Figure 33), I thought perhaps she would be interested in the way I organized the photographs. Ultimately, she was not interested in my particular ordering of these photographs because I had organized them by page in the yearbook. I believe Jordan had different ways of attaching meaning to each photograph and my organizational system did not match her own. Figure 38 shows various art supplies, a sketchbook, her phone, and photocopied images of a yearbook spread across her bed. The notebook shows a predetermined prompt I had created to elicit some of her school memories. Jordyn resisted my attempts to shape our time together and instead preferred to engage in more open-ended collaging activities using the yearbook photographs.

Figure 39. *Emoji Adhesives*

Figure 40. *My Premade Word Offerings*

Figure 41. *"Girls"*

Figure 42. *"Boys"*

Note: Jordyn took both of these photographs herself using my phone.

My last attempt to guide our research activities explicitly involved emoji stickers and written words. Knowing that she enjoyed using her phone, I thought she might enjoy adding emoji stickers to the collages as a way to code the images emotionally. Perhaps she would put a frown or poop emoji on a less preferred peer or a laughing emoji on a favorite teacher. Rather than use them to label images, Jordyn used the emojis to stick the images to a blank page (Figure 39). When I offered some written words, including "girl, boy, bully, happy, favorite, gross, fun, boring," Jordyn glanced at the selection, then quickly began collaging (Figure 40). After a few minutes, she selected "girls" and placed it on a collage of all female students; then she selected "boys" and attached the word to a collage of all male students. She then wrote the words "boys" and "girls" on two of the collages (Figures 41 and 42). She took my phone, took a picture of the collages, and put the originals in a stack on her desk.

After Jordyn used the written words on her collages, I experienced a sense of accomplishment. But what exactly had I accomplished? What did I learn from Jordyn's use of a word to label an image? I began to question my motives for pushing a particular word and language-based agenda. By pushing my own agenda with labeling, sorting, and identifying, I privileged my own perspective on communication over hers. Jordyn was fluently communicating

to me in her own language using gestures, body movements, and affect. In creating the collages, she showed a kind of intimacy with the objects. She made careful choices about how she touched and smelled the glue, the scissors, and the paper. I was so busy interpreting her actions through my lens of symbolic language that I missed *her* communication and missed moments to support *her* access needs.

Autism activist and leader in the neurodiversity movement Mx Baggs[1] illustrated their intimate experiences and relationships with objects in their short film, *In My Language* (2007). The first half of the film depicts the way in which their humming, rocking, flapping autistic body interacts with objects around them and how sie is in "constant conversation with every aspect of my environment." In the second half of the film, Baggs, a non-speaking person, uses an augmentative device to type out words that are spoken via a computer and displayed as written captions on the screen. Sie describes their sensory experience with objects such as moving their fingers across blinds, feeling the texture of a towel on their face, and smelling and looking closely at books as their "native language." Baggs argued that their native language is dismissed by non-autistics and it is only when Baggs can pair their actions with symbolic language (by typing out words that are expressed via augmentative device) that non-autistics view Baggs as a thinking person.

> It is not enough to look and listen and taste and smell and feel. I have to do those to the right things such as look at books and fail to do them to the wrong things or else people doubt that I am a thinking being.

I fell into the same ableist trap with Jordyn; because she did not use standard ways of communicating her thinking, I struggled to understand her intentions.

[1] Mx Baggs identifies as genderless and prefers the pronouns sie, hir, or they.

Throughout these failed research attempt,s Jordyn was exceedingly patient with me. When Jordyn set a boundary by saying “No thank you,” I always accepted and acknowledged it and never pushed an idea. In retrospect, I am a bit embarrassed that it took me so long to catch on. Jordyn was clearly telling me, “Let me do this my way.” Narrative researcher Frank (2010) stressed the importance of “not rushing the participant to tell the story that the researcher thinks he or she wants to hear” (p. 108). I needed to be more open to the story she wanted to share rather than the story I expected to learn.

By the second month of our work together, I began shifting my expectations and role. Rather than try to control or guide the sessions, I simply prepared the yearbook materials and art supplies and allowed Jordyn to take the lead in our meeting time. Rather than think about preparing symbolic words, I thought more about textures and sensory experiences. I brought different kinds of glue and writing utensils to offer various artistic sensory expressions to the collages (Figures 43 and 44). When I let go of my own agenda and prioritized communication preferences and interests, our relationship strengthened. Jordyn began showing more affect when I arrived each week and began greeting me more often with a smile and a “Hi Rae!” She gradually became less interested in her phone and would often have Candyland set up when I arrived for our meetings. Ada mentioned that Jordyn looked forward to our weekly meetings, talking about them during the week. If we had to miss a session, Jordyn was quick to remind me of our next meet-up date.

Near the end of our research, I learned the history behind Jordyn’s family photo albums that covered her room. Ada shared with me that when Jordyn was a teenager, she and Ada were in their home when it caught fire. Ada, recovering from knee surgery, had mobility challenges and struggled to move quickly. Once they were safely outside, Ada watched in horror as Jordyn

ran back into the burning building. Unable to chase after her, Ada's neighbor went after Jordyn and luckily both emerged from the building unharmed. Jordyn, Ada discovered, had run back into the burning building for her most prized possessions, her family photo albums. Photographs hold deep meaning for Jordyn. By altering them, I was inadvertently interfering with something deeply personal to her.

During each of our meetings, Jordyn created as many as 10 collages. After she finished each one, she handed it to me. I spent time examining the collages and if I knew students or teachers from the picture, I narrated a memory I had of that person. Periodically, Jordyn DJ'ed our meetings by pulling up music on her phone. On one occasion, we listened to the Roberta Flack song, "Killing Me Softly." The two of us sang loudly, seated on her carpet, surrounded by scraps of paper and Candyland cards. In the last month of working together, I really looked forward to spending time with Jordyn. The feelings of uneasiness, the lingering nagging presence of my research questions, faded and I was able to be fully present with Jordyn. The first month of our meetings, Jordyn frequently said, "No thank you," but during our last month of meetings, each meeting ended with Jordyn stating, "More please."

Figure 43. *Concentric Circles with Glitter Glue*

Figure 44. *Tactile Full Coverage Application*

Figure 45. *Jordyn Engaged in Careful Examination of the Yearbook Photos*

Figure 46. *Jordyn DJs in Her Office*

Sarah Pink (2015) wrote about the importance of hands in thinking about sensory-oriented ethnographic work: “The hand is an important focus in sensory ethnography research, particularly for understanding touch and tactile ways of knowing” (p. 168). The above Figures 43, 44, 45, and 46 show Jordyn’s hands at work as she engaged in the tactile experience of collage making. Jordyn took great pleasure in the various textures and visual aspects of glue application. When using Glitter Glue, Jordyn enjoyed using the fine-tip glitter pen to create concentric circles with the glue. Each edge of the paper was covered. Excess glue that squeezed out from the edges when applied to the paper would be neatly removed by Jordyn’s fingers and smelled as a way to experience the substance (Figure 43). Another preferred material included a particular Elmer’s glue stick that, when applied appeared, purple in color but dried clear. Jordyn used glue sticks in a more linear way and applied each stroke almost like a stroke of paint from a brush (Figure 44).

The research space with Jordyn often consisted of working from her bed. The above figures show Jordyn engaged in various research activities while seated in bed with her heavy and colorful quilt on her lap (Figures 43, 44, 45, and 46). Her favorite set-up was to sit cross-legged under the heavy quilt and lean back against the pillows. Splayed out in front of her were the research materials, which included glue sticks, markers, a photocopied yearbook, scissors, a sketchbook, her phone, the Candyland board, and various pieces and cards from the game. Jordyn’s bed and bedroom became the organizing space of our work. Disability activist and writer Leah Lakshmi Piepzna-Samarasinha (2018) noted that “capitalism says that disabled, tired bodies that spend too much time in bed are useless” (p. 181). Instead, she reclaimed the bed as a space of radical disability activism:

> I am a chronically ill queer of color artist, and so much of my time is spent in bed. I joke that my bed, heaped with cushions, is my office, my world headquarters. My life is arranged around my bed. (p. 182)

Jordyn's bedroom was her workspace and office, a place of comfort, safety, and creation. I was very lucky that she allowed me to share her most comfortable place.

"Believers and Non-Believers": Jordyn's School History and Transition to Adulthood

Ada described Jordyn as engaging with two types of teachers and therapists throughout her educational experience, "believers and non-believers." The "non-believer" educators and therapists continually underestimated Jordyn. The "believers," however, maintained high expectations of Jordyn and allowed her to show her strengths and knowledge in a variety of ways. These "believers" presumed Jordyn was competent. Disability Studies in Education (DSE) scholars have described presuming competence as the assumption that a disabled person is capable of thinking, learning, and understanding, even when that person uses an unconventional form of expression to display understanding (Biklen, 1990, 2005; Goode, 1992; Kliewer, 1998). Throughout her educational experiences, Jordyn flourished in environments where her interests were centered and adults spent time building rapport with her. In settings that emphasized compliance and rigid expectations of behavior, Jordyn fell apart.

Ada described carrying Jordyn in an infant sling during her brother Brandon's autism evaluation appointments. She remembered asking the doctor, "What about her? Should I be worried?" The doctor dismissed her concerns, "No, she's a girl. Autism never happens in girls." Jordyn met all of her early developmental milestones; she was a chatty child at 18 months old and had begun to string together short sentences. Consequently, Ada noticed right away when just before her second birthday, Jordyn lost her language abilities: "It was difficult to watch somebody who was moving pretty quickly along her milestones and then just stop and regress."

Having already been through the process with Brandon, Ada and Joel were quick to seek out an evaluation for Jordyn and knew what doctors and specialists they needed. Yet their experience with obtaining services and support for Jordyn was consistently more difficult, as compared to their experience with Brandon; "from the beginning it's been a fight to get her services," Ada explained. "With Brandon, things were much easier. Jordyn has a more complicated profile." Although the couple had all of the knowledge and tools to navigate the diagnostic process, they experienced immediate pushback from clinicians. Ada explained:

> In the very beginning, people were saying, "You're over-reacting. She's fine. Let's just wait and see." The overall feeling was that autism was so rare in girls and also Jordyn was really social and wasn't rigid about her schedule, so all of the specialists kept dismissing me.

Part of the resistance for Jordyn was the constant comparison to her older autistic brother. Brandon fit what Ada described as a kind of "stereotype" of autistic behavior:

> He likes trains. Oh, he's into cars. He could recognize every car brand and every model and the whole bit. He displayed a lot of the things you would expect to see or what you read about in the literature, what the kids with autism do, the lining the stuff up and this repetition.

This description of a "stereotypical" autism profile aligns with a male presentation of autism (Dean et al., 2014; Dean et al., 2017), and Jordyn, who was social and connected, did not fit the profile.

Research has shown that girls are diagnosed both at a lower rate and at an older age as compared to boys (Begeer et al., 2013; Giarelli et al., 2010). These diagnostic gaps are even more prevalent for Black girls who typically receive a diagnosis much later, compared to their White peers (Zeleke et al., 2019). I wondered if Jordyn's status as a Black girl had impacted her diagnostic experience. However, Ada believed that economics had a larger part to play in her children's access to services than race. I asked her explicitly if she felt that Jordyn's later

diagnosis was connected to racial bias from clinicians. Having had two Black children diagnosed as autistic, Ada experienced a noticeable difference with her Black daughter, as compared to her Black son.

> I did not feel that, honestly. I do know there is racism. I'm clear about that. I also think there is a lot of resources are just based on how much money you have to spend. I was lucky. I could pay for things. I could pay at least a year's tuition at Oakdale and be able to get through. A lot of people couldn't even have done that. I think that the bigger problem is just if you're not in the top ten percent on the social economic scale, you are denied.

Research has supported Ada's experience that socioeconomic status and access to healthcare are huge contributing factors to receiving an autism diagnosis (Durkin et al., 2017; Pulcini et al., 2017). From Ada's perspective, the resistance from specialists was more due to their insistence that girls did not have autism and that Jordyn presented much differently than her brother.

Due to her language regression, Jordyn began attending a special education preschool program when she received Special Education Itinerate Services (SEIT), or specialized supports from a special education teacher, and speech therapy. While pursuing a diagnosis for Jordyn, several clinicians suggested to Ada that Jordyn had intellectual disabilities instead of Autism. Ada described the back and forth between clinicians:

> They'd say, "Well, maybe she's not autistic because she's so social and empathic. This is just an intellectual developmental problem." I'd go, "No, I think this is just a different brand of autism." I just don't really think that people were willing to be flexible because they didn't know.

It took the family 18 months to finally receive an autism diagnosis; Jordyn was 3½ years old.

Compliance-based Programs: "She didn't fit into the model."

For kindergarten, Joel and Ada were happy to have Jordyn attend the same school as her older brother. The Focus School is a private school with small class sizes designed to support children with disabilities. The school was welcoming to Jordyn in part because Brandon made

great progress in the program. In the first 2 years, Jordyn flourished. Her teacher had a nurturing quality. Ada described this teacher as having a "belief" in Jordyn's ability to learn, and during these years, Jordyn made meaningful progress in her language development. During Jordyn's third year at the school, she was placed in an exclusively Applied Behavioral Analysis (ABA) classroom. Tasks were broken down into small pieces and presented to Jordan as a series of activities. External reinforcers such as praise, stickers, tokens, or food were used to reward her for completing a task successfully (Lovaas, 1987; Silberman, 2015). For a further explanation of ABA, please refer back to Chapter II.

Jordyn's first year in the ABA classroom was a complete disaster: "She completely fell apart. Everyday she'd come home from school crying." Ada described that the compliance-based behavioral approach in the ABA classroom negatively impacted the way the teachers viewed Jordyn: "ABA made them look at her differently." Rather than being strengths-based and having a nurturing stance towards her, teachers who used ABA with her viewed Jordyn as a behavioral problem. Compared to her previous teacher who had a belief in Jordyn's ability to learn, this classroom teacher had very low expectations for Jordyn and was what Ada described as a "non-believer." These teachers filtered Jordyn's actions through a lens of "appropriate and inappropriate behavior." When she displayed independent thinking or expressions of compassion towards her classmates, Ada described that Jordyn's actions were viewed from a deficit perspective and an expression of Jordyn's non-compliance.

> She was scolded for doing kind things, like sometimes kids would cry and she'd get out of her seat and she'd go, "Don't cry. Don't cry." And the teachers would say, "Jordyn, back in your seat." She's hearing someone cry and she's responding to that and she shouldn't be penalized but she was. She was considered a behavior issue.

Jordyn's strength in social connections and expression of empathy was viewed as a class disruption. Ada described that Jordyn initiated less often with peers in this kind of environment.

Ada did not recall Jordyn forming friendships at Focus and mentioned that Jordyn was most often the only girl in her classes; “there were so few girls in the entire school. She only shared a classroom with one other girl, Melanie, once. Melanie also had a very negative response to ABA. She didn’t fit the model either.”

Jordyn stayed at the school for a total of 4 years. Ada remembered feeling trapped, and when she attempted to advocate for Jordyn, pointing out that the behavioral approach was not working for her daughter, she was dismissed.

> All of the experts insisted that Jordyn should be in an ABA kind of program. It was considered the gold standard of autism intervention. I kept telling them that it was not working for her. I watched her regress in the ABA. I kept telling everyone that this is just not how she works.

Jordyn pushed back against external reinforcement. External rewards did not motivate her participation in classroom activities. Ada explained:

> Everyone thought she should be able to sit down, and they would give her a couple of Skittles and she’d get to the task. But she’d basically just wait them out. That model and getting her to try to respond on a behavioral basis just didn't work. She’s always been someone who looks to the gray shade. It’s not a black and white world for her.

During Jordyn’s fourth year at Focus, Ada and Joel were advised by the school’s director that Jordyn needed to find a new program because she “wasn’t a good fit.”

In third grade, Jordyn transitioned to another private special education program, Maple School, that used the TEACCH model. TEACCH is a model similar to ABA in that it is a structured behavioral program that involves a series of rewards for completing specific tasks (Callahan et al., 2010). Ada believed that the program’s emphasis on using visuals to support language development would work well for Jordyn, given her strong visual memory. Maple School, however, was a disappointment. The staff was not well trained; Ada was specifically

frustrated by the way the staff approached language acquisition. She described what she saw on a classroom visit:

> They would go up to Jordyn with a picture. They wouldn't say a word, they would just point to the picture. Jordyn was supposed to say the world like "dog" or whatever. Well, she would say "dog" and then they would put up the next picture. I'm like, "Wait a minute. You're supposed to say, 'Jordyn, that's great. That's a dog. What does the dog do?" But they didn't get that part. Language wasn't put into social context at all. It made me almost lose my mind.

Although visual supports were a promising approach given Jordyn's learning style, because the intervention was implemented without the context of social language, Jordyn was not able to generalize her language skills beyond the structured classroom setting.

Ada and Joel became even more disillusioned with the Maple School when they made the shocking discovering that Jordyn suffered lead poisoning from the school's swimming pool. The school's newly refurbished pool had not been sealed properly, which led to the leaking of lead paint into the water. Jordyn and other children in the school tested positive for dangerous lead levels in their blood. Ada and Joel promptly removed Jordyn from the school and contacted a Special Education attorney to help them identify a new school setting for Jordyn.

Finding a Good Fit: "They brought out her inner diva!"

Joel and Ada took a big risk when they enrolled Jordyn at Oakdale Academy. When they toured the school, it had not yet opened and was, in fact, still under construction. The school also used a different model of teaching than the models at Maple School and Focus. Rather than using a behavioral-based intervention, Oakdale used a constructivist approach called DIR Floortime. DIR Floortime does not use external reinforcers to motivate student learners. Instead, the approach incorporates children's interests into activities to increase student engagement (Greenspan & Wieder, 1997). Oakdale was one of the first schools to employ the model; DIR

had previously been primarily employed by individual therapists or parents. Building strong relationships between teachers, students, and peers was a huge focus of the school program.

Jordyn began attending Oakdale Academy in its inaugural year as a middle schooler and joined a small classroom of seven other children, six boys and one other girl. I joined Oakdale the same year as a teaching assistant in a first grade classroom. Ada noticed an enormous change in Jordyn immediately: "When she went to Oakdale, everything in her life changed. I think she recognized her inner diva." Before enrolling at Oakdale, Jordyn wore noise-cancelling headphones and often covered her face with her hands, "almost like she didn't want people to see her." Just after starting Oakdale, Ada saw a shift in her self-confidence, "All of the sudden she started standing tall. She strutted."

Ada noticed and appreciated the very different approach Oakdale teachers took with Jordyn. Rather than focus on behaviors, they focused on building a strong relationship with Jordyn and invested a significant amount of time trying to understand her interests and communication styles. Teachers at Oakdale were "believers" who spoke to Jordyn with respect, with an expectation that she understood what they were saying. Ada described that at Oakdale, there was an overall commitment to supporting and understanding Jordyn.

> Every single teacher at Oakdale was great. Every single teacher really was a believer. They saw that sparkle in Jordyn. Everyone saw her spirit and appreciated her.

Ada mentioned three teachers with whom Jordyn showed a special connection: "Jody had a very gentle soul. Natalie and Amelia just seemed to really get Jordyn. They had a real insight with Jordyn." Jordyn featured the images of these three teachers often in her collages (Figures 47 and 48). As Jordyn became more comfortable at Oakdale, she began to participate more eagerly in class activities:

> You can't make her do things. She has to be motived to do it on her own. Things had to be much more naturalistic for her to do them. People who have expectations and make that clear to her she always rises to the level.

Jordyn's interests in arts-based activities and her strength in visual learning were big aspects of her curricular program.

Figure 47. *Jody's Class at Oakdale Academy*

Figure 48. *Amelia's Class at Oakdale Academy*

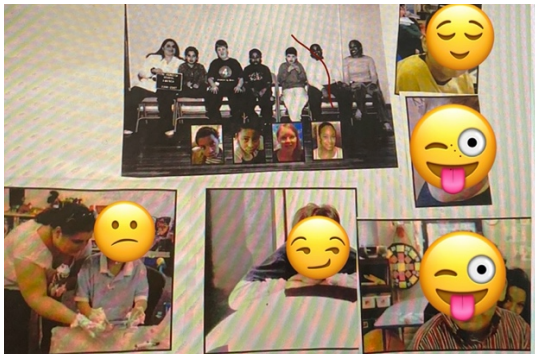


Figure 47 and Figure 48 are photographs from collages that Jordyn created using photocopied pages from an Oakdale yearbook. Jordyn selected each of these images to group together. I digitally placed emoji icons on the faces of students and kept the images small to maintain their privacy. I chose an emoji that most closely matched the facial expression of the student. In both of these collages, Jordyn heavily feathered the three teachers that Ada described above as "believers." These two particular collages stand out because Jordyn is featured in both of them, which was not common across the other collaged images.

One of the biggest therapeutic supports at Oakdale were the sensory-trained occupational therapists (OTs). OTs are trained to support individuals in the area of motor development (Murray, 2012). In Jordyn's other schools, her OT sessions were focused more on improving her handwriting; at Oakdale, her OTs were trained in understanding and supporting Jordyn's sensory

system. Through a series of play-based activities, therapists worked with Jordyn to integrate her sensory systems so that, for example, she was not as sensitive to noise, making it easier for her to remove her headphones both in and out of school. In several of Jordyn's collages, she featured students using the sensory gym, a space where she engaged in OT (Figure 49). It was at Oakdale that she also began receiving play-based mental health counseling from a school psychologist: "it was fabulous and made a huge difference." The combination of occupational therapy and counseling really helped with Jordyn's overall self-confidence.

Peer interactions continued to be difficult for Jordyn and she usually gravitated towards the adults in the classroom rather than her peers. Over the 6 years that Jordyn attended Oakdale, she was always in a classroom with one other girl. Ada mentioned that of all her peers, she tended to connect better with other girls. In many of her collages, Jordyn featured the other girls who attended Oakdale. During our research meetings, Jordyn seemed to pay closer attention to photographs that featured girl students. Because there were so few girls in the school as compared to the boys, matching the national average of four boys to every one girl (Maenner et al., 2020), Jordyn had to search for images of girls across many pages of the yearbook (Figures 50, 51,

and 52). Below she labeled the picture "girls" (Figure 51). Despite the supportive structure of Oakdale, there were several times throughout her school experiences when Ada felt Jordyn was overshadowed by other students, male students, who had "more challenging behaviors." Ada described that Jordyn was often overwhelmed by the unpredictable nature of some of her peers.

Figure 49. *Kids Playing in the Sensory Gym*

Figure 50. *Girls Having Fun*

Figure 51. *"Girls"*

Figure 52. *Girls + Emojis*

Jordyn was 17 when she entered her sixth year at Oakdale Academy, and she was making meaningful progress both at school and at home. Ada felt that the relationship model at Oakdale was in sync with the way the family supported Jordyn at home: "Living the relationship model at school and at home was most beneficial for her. It was a godsend for her." Things, however, took a terrible turn when the family experienced a traumatic housefire. The fire had vast implications for the family. Because the family had to invest a great deal into repairing their home, Jordyn was not able to return to Oakdale Academy, which was a private school. In 1 year, Jordyn lost her home and the security of a safe and supportive school environment. Ada described the experience: "The trauma of our house fire was really really difficult. We lost everything." Jordyn was a few years away from graduating at the age of 21 and the family had to look for yet another program.

Transitioning out of Oakdale and Towards Adulthood

"It's been hard for her to make peace with the world she's in right now"

Leaving Oakdale was very hard on Jordyn. The family scrambled to find a good program for Jordyn, but ultimately had to settle for a school they found unsupportive and uninspiring. The last 3 years of Jordyn's education were spent at the Mason Institute. Mason relied on behavioral techniques and again Jordyn regressed. Ada described that the teachers at Mason were non-believers who held a deficit perspective of Jordyn.

> When she first went to Mason, she was with a teacher who did not get her spirit at all. I think she was quite mean and got her kicked out of that classroom. That was her worst of all of her years of school. Jordyn would again come home crying. I know she missed Oakdale. The teacher was not a believer. The teacher felt like she was subpar. She had no expectations for Jordyn.

The only silver lining at the Mason Institute was its job training program. Towards the end of her time at Mason, Jordyn began participating in this program, which brought her into the community. Accompanied by a counselor, Jordyn enjoyed being out in the community: "She's a relationship person, so being with someone she trusted was much better for her." Jordyn's affinity for community-based activities gave the family hope for her transition out of school programming and into adult services.

Jordyn began participating in Prospect Community Supports adult day program after graduating from the Mason Institute 3 years ago. Before the pandemic, she would attend the program 5 days a week. A bus from the program would pick her up at 7 a.m. and she would return home on the bus around 4 p.m. Ada described the program as a huge waste of Jordyn's time.

> I'm really unhappy with her day program. I'm always asking Jordyn what she does at program and she always says nothing. They literally have her doing nothing all day. I think they just have them watch TV all day. It's terrible. I hate it.

Although Jordyn has attended the program for years, she does not appear to have made strong connections with any of the staff or other adults in the program.

The very thing that Jordyn was supposed to receive through the program, job training, is now no longer part of her program. When she first started at Prospect Community Supports, Jordyn was accompanied to a clothing store. Rather than engage the adults in meaningful job training, Jordyn and her fellow participants were instead tasked with low-skill activities like folding shirts. When she completed the task, she began to explore the other shelves of clothing and, rather than understand this as her way of being interested, the job coaches viewed her as a kind of flight risk. Ada explained:

> She doesn't go to internships because they say she wanders, but it's just that she's bored. They took them to Marshalls and had them fold clothes and she was done folding ten shirts in like two minutes and then she didn't have anything to do, so she started to walk around, and they called that wandering, so now she doesn't go out anymore.

It is extremely frustrating for Ada to see adults from the adult program once again underestimate her adult daughter. Similar to the teachers from Jordyn's past who viewed all of her actions through a lens of deviance, staff from the adult program assign malicious intent to Jordyn's interests. For example, Jordyn enjoys collecting items in plastic bags. When she took home several markers from the program, a staff member called Ada and accused Jordyn of "stealing."

Before the pandemic, Ada was working hard to find meaningful work for Jordyn and a series of activities and routines that gave her daughter joy and a sense of purpose. Ada was pursuing a process called self-directed funding, which means families receive more power and control over the funding for their adult children. Rather than money going directly to programs, families, in collaboration with their adult children, can hire their own support staff. This allows for programs to be more flexible and tailored to specific individuals' interests. Ada had been

pursuing self-directed funding for over a year when I began working with Jordyn and had still not received the approval when we ended our research a year later. One of the hurdles in the process was to have Jordyn have a more recent evaluation report. During Jordyn's evaluation, the White male physician challenged the credibility of Jordyn's identity and diagnosis. Ada described the story:

> He turned to me and said, "I don't think she has autism. I think she has an intellectual disability." I turned to him and said, "We've been dealing with this for a while. She's twenty-five years old." It just took me back twenty years ago to old labels of what autism is supposed to look like.

It had been more than 20 years since Jordyn's first evaluation, yet some things had not changed. Clinicians were still stuck in a particular gendered and racialized perspective of autistic identities.

Ada dreamed of creating a relationship-based program for Jordyn in her adulthood. Building on her success at Oakdale, Ada wanted Jordyn to pursue her interests and find meaningful work.

> Jordyn loves to grocery shop. She knows our store really, really well. Our grocery store said she could work there, and they would take her on, but they would need someone to come with her. That's all I need is someone to support her because she is capable, and she can do things.

One of the last times we were able to meet in person, I went to the grocery store with Ada, Brandon, and Jordyn, and witnessed the way that Jordyn expertly navigated the enormous grocery store. She easily moved around shopping carts and crowded isles. She took out her list and began shopping for produce, sorting each category of items into individual bags (ex: all the lemons were together, all the limes together).

While on our shopping trip, I was also able to witness the dynamic between Ada and Jordyn and the closeness of their relationship. Ada holds a deep fundamental belief in Jordyn's

abilities and advocates for a world that sees her daughter with the same strength-based lens. There are subtle yet powerful ways that Ada supports her adult daughter's perspective and opinions and also holds space for humor in their relationship. Throughout the shopping trip, Ada and Jordyn were in constant conflict over the grocery list. Jordyn repeatedly tried to go off-list and add preferred items to the cart. Ada would insist that Jordyn stick to the grocery list: "Those are too expensive, Jordyn," she would say to her daughter with a smirk. The minute that Ada turned her back, Jordyn would place the expensive item into the cart—a bar of chocolate, a nice smelling soap, or an exotic mushroom. A few minutes later, Ada would laugh when she discovered the contraband items. Jordyn would shoot her mom a sly smile. The back-and-forth continued until Jordyn created her own loophole by adding her preferred items to the list. She quickly wrote "Canada Dry" on the paper, placed a case of ginger ale in the cart, and then crossed it off the list (Figure 53).

Figure 53. *Canada Dry, Mushrooms, and Pork Roast*

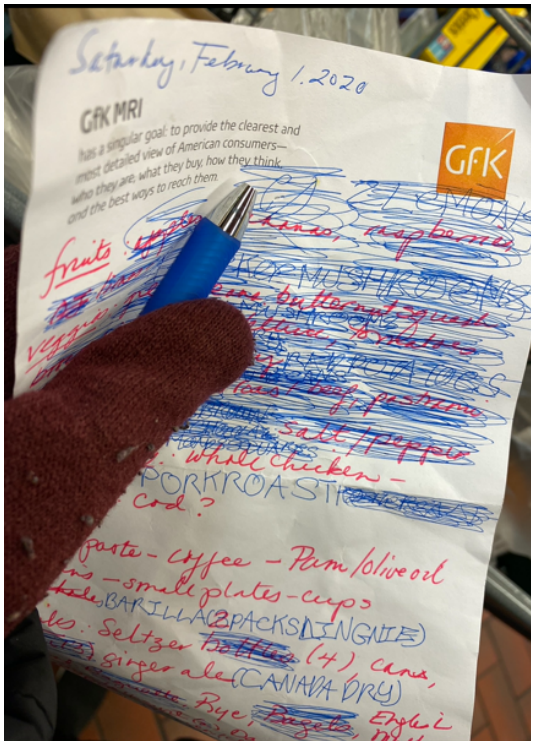


Figure 53 is a photograph taken of the Johnson family grocery list. Ada penned the list in red ink. Jordyn has crossed off all retrieved items using a blue pen and has also added her own additions to the list, including “pork roast, Canada Dry,” “potatoes,” “mushrooms,” and “Barilla Packs Single.”

In another instance at the fish counter, Ada demonstrated that she prioritized Jordyn’s way of organizing her world. Ada had planned to buy a particular type of fish, but then learned that it was out of stock. Jordyn became irritated that the item of “seafood” was unchecked off of the list, so she suggested alternatives to Ada: “Salmon. Crab legs. Clams.” Jordyn insisted that her mother buy a seafood item. After the two negotiated for a minute or so, Ada agreed but at that point, three additional customers had joined the line. Ada and Jordyn waited patiently for their turn again and Ada bought clams. Jordyn wrote “clams” on the list and then scratched it off. In this small moment, Ada shows a confidence in her daughter, a belief that what Jordyn was communicating was meaningful and important to her. Ada is Jordyn’s biggest “believer” who prioritizes Jordyn’s sense making, understanding that for Jordyn, this was no small thing and would perhaps be something that would bother her—an unfulfilled item on the list. Rather than try to impose her own logic, Ada acknowledged her daughter’s reality, the importance of completing the task. By doing so, Ada honored her daughter’s communicative gestures. Ada and Jordyn are working hard to create a future where Jordyn is seen for her humor, her talents, and her heart. Ada needs the world to see her daughter the way she sees her: “She is capable, and she can do so much.”

AFTERWORD

It is 2:37 in the morning. My phone, which is plugged in at my bedside, lights up with texts. At first, I am worried it is an emergency. In a half-awake state, I look at my phone and discover 76 text messages from Jordyn. It had been months since I had seen her. When the pandemic started, I stopped my visits for safety reasons. Jordyn's family experienced real hardship in the spring. Joel had contracted COVID early and had to be hospitalized. None of the family could visit and Ada was very scared that he would not make it. Thankfully, he was released from the hospital and made a long and slow recovery at home. I was in regular contact with Ada during those first few months. I was very worried about Joel and the risk of the rest of the family contracting COVID. I also was frustrated that I did not have any kind of closure with Jordyn at the end of the research. It simply ended. At one point when the entire family was quarantined, I was able to drop off some groceries and could see Jordyn through the glass door. I heard her ask, "Rae play Candyland. COVID will be over on April 19th." If only she was right. Finally, I sent a package to Jordyn as a thank you for all of the time she spent with me. The package included a polaroid camera, some film, and some Glitter Glue. Not one for Zoom or FaceTime, I was not sure when I would next hear from Jordyn.

The next morning when I wake up, I look at each of Jordyn's texts. Each of the 76 text messages is a picture followed by a descriptive caption. Many are pictures of family photos, either framed or from photo albums. The first picture in the series is a blurry picture of Ada with the caption, "Mom I'm going out tomorrow" (Figure 54). *Most pictures show the family of four on various vacations. They are seen happily smiling into the camera while riding a boat on a dolphin watching cruise, in Disney world, or at family events with her cousins. Jordyn sent pictures of a favorite meal* (Figures 56 and 57). *There were approximately 20 close-up pictures*

of her Christmas tree and ornaments (Figure 58). *She also sent beautiful selfie pictures of herself and her mom with the caption, "Mom and Jordyn I am happy 😃!!" I remember Ada telling me that Jordyn will send her these kinds of photos and that, in quarantine, Jordyn has begun reaching out to her cousins with similar texts.*

Over the next few months, Jordyn sends these kinds of texts periodically and I respond with my own. "Here's me and M making Valentine's together." "Look it's our Christmas tree." "Here's my grumpy cat refusing to get off of the counter." Despite the fact that we cannot be together in person, we continue to share our lives in pictures. I share her photograph below and use her own descriptions as the figure headings.

Figure 54. *Mom I'm Going Out Tomorrow*

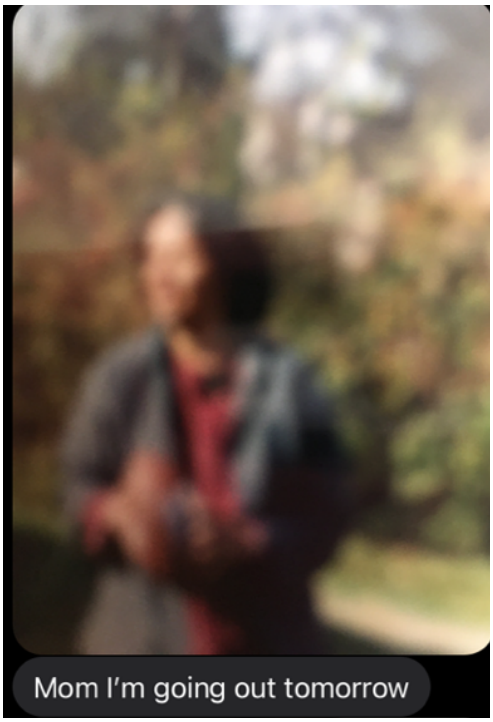


Figure 55. *Brandon I Can't Wear the Glasses and Nose!*

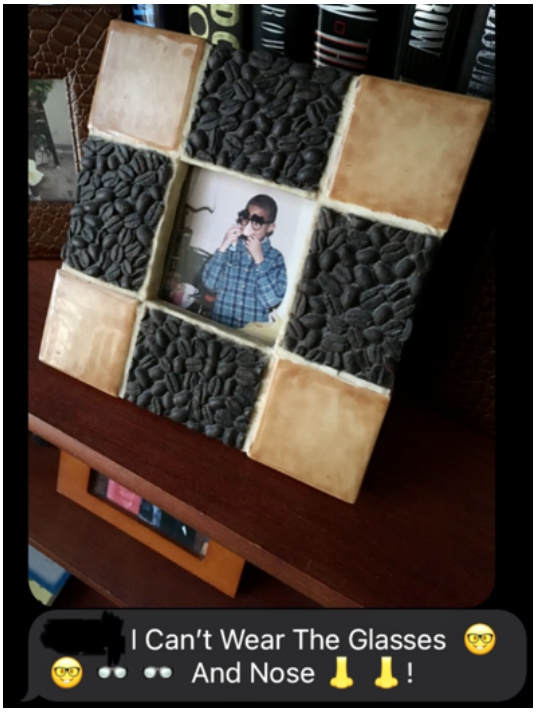


Figure 56. *Chili White Beans and Red Beans and Corn Bread*

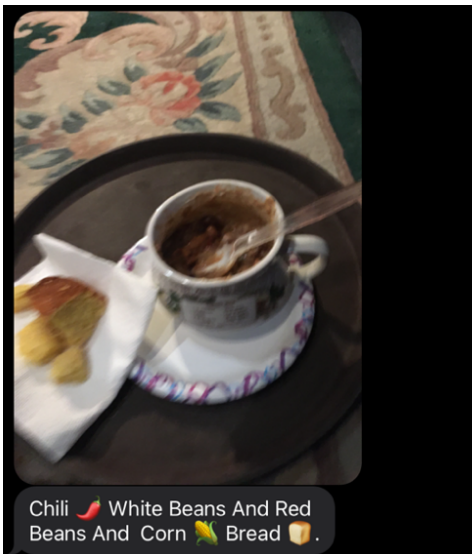


Figure 57. *Are You Made It a Sour Cream Pound Cake*

Figure 58. *Christmas Mini-Gold Ornament?*

These series of photographs illustrate essential aspects that I have learned about Jordyn. It is no coincidence that the first image she sent is of Ada (Figure 54). *Ada and Jordyn are so intimately linked, and each woman has a deep sense of understanding and knowing the other. Family is the most important thing in Jordyn's life, and she shares those happy memories from her childhood of times with her brother* (Figure 55) *or family vacations. Food is also important to Jordyn and their family, and due to Ada's amazing cooking, she is always surrounded by delicious full-sensory experiences like the spicy chili* (Figure 56) *or the homemade poundcake, which is shown in the family kitchen where I spent so much time chatting with Ada at the kitchen table* (Figure 57). *Figure 58 is a photograph Jordyn took of a Christmas ornament. You can see her hands holding her pink eyephone case in its reflection.*

CHAPTER VII: DISCUSSION AND IMPLICATIONS

Returning to the Micro and Macro

Joelle and *Cats.* In the first chapter of the dissertation, I began with a "micro" story about Joelle, a 15-year-old autistic girl who was a student at the school where I worked at that time. Joelle was one of the few girls in the entire school. Her passion for the musical *Cats* (Weber, 1981) was not shared by her male peers, so I started an affinity group with just the two of us. We practiced and performed *Cats* lyrics in my cramped office. I have held this memory close to my heart for years, but I lost touch with Joelle when she moved across the country nearly 10 years ago. During the pandemic, however, I received a text from the now 23-year-old young woman. She and I began corresponding occasionally, sharing little stories about our lives. In one of her emails, she described her memory of the *Cats* group and reflected on how she felt about that time, "I. Remember to. Smile. And. Be happy and. Do your. Best. And. Also. Remember. What. Happiness is"

Julia at the UN. In the "macro" vignette that I shared in Chapter I, I recounted a speech that Julia Bascom gave at the UN World Autism Day. During her speech, she reminded the audience that "autistic women have always been here" and to "listen to autistic women. Stop speaking over us, stop trying to help, stop insisting that we are the voiceless in need of a voice, and just listen. Just listen. Because we know what we need and we got this" (addressing the UN on April 2nd, 2018).

The inspiration for this dissertation came from seeing autistic girls in schools and wondering what more teachers and programs could do to be more responsive to their needs and interests. I wanted to learn more about their experiences and relationships or, as Joelle so poetically described, create "What. Happiness is" and the ways in which schools did not center

these girls (now women's) experiences. I wanted to see what went unnoticed within wider conversations about autism and autistic people that equated autism with masculinity. From a research perspective, I wanted to think more deeply about accessible research methodologies that allow for a wider range of communicative expressions and to explore emancipatory research methods that focused on the autistic experience rather than on autistic bodies and genomes. How could I approach a research project with Julia Bascom's call to "just listen" (Bascom, 2018) as a central and organizing orientation for the project?

In Chapters IV, V, and VI, I shared Kelly's, Zula's, and Jordyn's school stories through their own words and the words of their mothers. Their stories were also shared through their pictures, artwork, interests, movements, resistance, and silences. In these chapters, I privileged the participants' perspectives and the experiences of their mothers. In doing so, I also shared my own reflective process. In the crafting of their stories, choosing their quotes, writing the vignettes, choosing the titles and image descriptions of photographs, I engaged in interpretation. I actively co-crafted these narratives.

> We do not *find* stories; we make stories. We retell our respondent's account through our analytic redescriptions. We too are storytellers and through our concepts and methods—our research strategies, data samples, transcription procedures, specifications of narrative units and structures, and interpretive perspectives—we construct the story and its meaning. In this sense the story is always co-authored. (Mishler, 1995, p. 117)

In this last chapter, I work to "transfigure the story's commonplace in light of a broader context" (Kim, 2016, p. 229). What do Kelly's, Zula's, and Jordyn's stories tell us about the autism diagnosis, gender, support systems, schooling, and research design?

The Goldilocks Dilemma: The "Just Right" Autistic Girl

In Chapter II, I outlined the literature around gender and autism. Overwhelmingly, research that has examined autism comes from a positivist perspective and is focused on

causation (Glassford et al., 2016; Halladay et al., 2015; Lai et al., 2011). Additionally, research that includes gender as a relevant area of inquiry is extremely scarce; the silence maintains the "myth that autism is significantly a male-dominated condition or alternatively that gender is not a consideration" (Hendrickx, 2015, p. 22). The small percentage of literature that did examine gender as an aspect of autistic experience did not include interviews with autistic women (Mandy et al., 2012); therefore, the research was conducted *about* autistic people rather than *with* autistic people.

Research has confirmed that women are diagnosed with autism at much lower rates compared to men, resulting in a 4:1 ratio gap between boys/men compared to girls/women (Maenner et al., 2020). Women are diagnosed later in life compared to their male counterparts (Begeer et al., 2013; Giarelli et al., 2010) and to receive a diagnosis, girls have to display more cognitive impairments and more obvious behavioral problems than their male peers who receive a diagnosis (Dworzynski et al., 2012). Black and Latino children are diagnosed much later as compared to their White peers (Durkin et al., 2017; Pulcini et al., 2017). A recent study measured that Black children received, on average, an autism diagnosis 3 years after their parents first brought up concerns to healthcare professionals, despite the fact that participants in the study had access to health insurance (Constantino et al., 2020).

In this chapter, I want to weave my participants' experiences in with these larger statistical data trends. Integrating my participants' stories into these larger conversations around statistics and diagnostic rates is an important aspect of disrupting these positivist narratives of causation and adds a much-needed contextualization about the lived experiences of autistic women and girls (Bogdan & Biklen, 2007). I first examine the timing of each of my participants and how that fits into a larger conversation around issues of access. Following that, I examine the

ways in which a Disability Studies and Critical Race Theory (DisCrit) lens can unpack how these women were read in schools through racialized and gendered constructions of "goodness," "smartness," and "fitness."

Timing of the Diagnosis

Each of my participants and their mothers spoke about their experience of receiving an autism diagnosis. Kelly, a White 28-year-old autistic woman, is considered part of a large group of autistic women who are "late diagnosed" (Bargiela et al., 2016; Mandy et al., 2012). Kelly began self-identifying as autistic at the age of 18 and received a professional diagnosis at 19. When pursuing a diagnosis, Kelly was concerned that medical providers would either not believe her or give her an entirely different mental health diagnosis. She had already received an ADHD diagnosis as a high schooler, a diagnosis she believes was incorrect: "ADHD was what people who were autistic but talked and were female got in the 2000s." Kelly worried that if she appeared to be "too verbal" or "too academically successful," she would not be read as autistic. Misdiagnosis is a common experience for many autistic women (Begeer et al., 2013; Giarelli et al., 2010). Because Kelly and her mother had access to quality health insurance through her mother's university employment, Kelly was able to receive a diagnosis which led her to receive accommodations in college and therapeutic support from a trained mental health provider with expertise in autistic women.

Jordyn, a 26-year-old Black woman, was diagnosed at 3½ years of age, but only after her parents pursued a diagnosis for 2 years while working with multiple clinicians. This fits with the data suggesting that the concerns of Black families are often ignored by healthcare professionals (Constantino et al., 2020). Ada, however, believed that the delay in a diagnosis was connected to Jordyn's gender rather than her race. Jordyn's mother, Ada, recognized the autistic expressions

in her daughter when she was 18 months of age. Having gone through the process of having her Black son diagnosed with autism, Ada was equipped with the knowledge and connections to have Jordyn evaluated. For years, clinicians dismissed Ada's concerns because Jordyn was "too social" or because "autism never happens in girls." Instead, clinicians suggested that Jordyn had intellectual disabilities. Ada's successful and relatively easy experience with getting her son evaluated led to her strongly belief that Jordyn was read differently because she did not fit a particular male presentation of autism. After 2 years of consulting different diagnosticians, Jordyn received a diagnosis of autism.

Of the three participants, Zula, a White woman who is now 26 years old, was the youngest when she received a PDD-NOS diagnosis. At the time of her diagnosis, PDD-NOS was considered to be under the umbrella of autism (Gernsbacker et al., 2005). At the age of 18 months, Zula did not display verbal speech, experienced periods of shut-downs when she was under-responsive to her environment, and had periods of what her mother Patricia described as "tantrums." During these toddler years, Zula had difficulty attending to group activities and was asked to leave a toddler play group because she was "not a good fit."

Putting these three women's diagnosis stories together reveals a specific narrow criterion that a girl or women must possess to receive an autism diagnosis. Kelly was "too smart" and therefore her autistic identity and access to accommodations were only achieved much later in life when she could advocate for her own needs and experiences. Jordyn was "too social" and did not fit the stereotypical male expression of autism that is perpetuated by researchers like Baron-Cohen (2003). Baron-Cohen argued that autism was a version of the "extreme male brain"; therefore, when Jordyn showed social connection and expressions of concern for others, clinicians read her behavior as incongruent with their masculinized conception of autism. Of the

three participants, Zula received her diagnosis at the earliest age, 18 months. Her profile fell within the narrow range of *what was allowed to be* autistic girlhood. At the time, she was very young, did not have verbal speech, and experienced frequent periods of distress during which her mother described her as "difficult to manage." Researchers have noted that for girls to receive a diagnosis, they often have to appear with more pronounced cognitive or verbal impairments and behavioral problems that align more traditionally with their autistic male peers (American Psychiatric Association, 2013; Dworzynski et al., 2012).

There are cascading consequences for children who are not given the proper diagnosis and are thus not provided with the proper supports and accommodations. Research has supported the importance of receiving a diagnosis and documented the negative impact a delayed diagnosis can have on a child, especially in the areas of communication (Mayo et al., 2013; Volkmar, 2014), cognitive development (Constantino et al., 2020).) and sensory processing (Pfeiffer et al., 2011; Porges, 2021). When children go undiagnosed or are misdiagnosed, they may not have the tools necessary to navigate school settings successfully. Without a diagnosis, girls like Kelly, who are struggling with sensory sensitivities and peer dynamics, go unsupported and are labeled a "problem." Ultimately, Kelly internalized these unnamed challenges, thinking that something was wrong with her. This is a common sentiment with other late-diagnosed autistic women (Ballou, 2017). In receiving a diagnosis, an autistic woman spoke about a sense of relief: "It was like taking off a corset I didn't know I was wearing. I could finally breathe" (Campbell, 2018, p. 28). Having an autism diagnosis allows girls and women to be better advocates for themselves, gives them a better sense of how others may see and interpret them, and, perhaps most importantly, provide an essential lifeline to other autistic communities—a concept I explore later in this chapter.

DisCrit and Constructions of "Goodness," "Smartness," and "Fitness"

Applying the critical lens of DisCrit to these women's stories revealed ways in which these women were understood and read through racialized lenses throughout their school lives. DisCrit examines the ways that ableism and racism work together to uphold notions of normalcy; "racism and ableism are normalizing process that are interconnected and collusive. In other words, racism and ableism often work in ways that are unspoken, yet racism validates and reinforces ableism, and ableism validates and reinforces racism" (Annamma et al., 2016, p. 14). Authors working in DisCrit have argued that a critical perspective of race and disability must be paired together to understand schooling trends that, for example, show that students of color are more likely to be placed in segregated school settings as compared to their White peers (Beratan, 2008). Interwoven throughout my participants' narratives were themes of "smartness," "goodness," and "fitness." DisCrit scholars have argued that Whiteness, goodness, and smartness are "inextricably intertwined systems of oppression and exclusion" (Leonard & Broderick, 2011, p. 2226). These constructed labels were applied to these women as young children in racialized ways in order to sort, reprimand, contain, and exclude them in school settings.

As a young White girl, Kelly was often celebrated for her intelligence. As an early reader and an extremely verbal child with a propensity for animal facts, Kelly was often labeled as "smart" by her teachers starting as early as preschool. Because she was seen as intelligent, her play was understood in capacity-oriented ways. For example, in preschool when she would engage in repetitive play of labeling colored balls in a ball pit, her teachers saw this as a way that she was organizing and labeling objects rather than a fixation. Kelly explained:

> The teachers saw this as me being really smart and knowing my colors. That is how adults will see kids who aren't diagnosed differently. They pathologize the behaviors of the kid with a diagnosis and redirect the kid away from what they are doing.

DisCrit scholars understand Whiteness and Ability as forms of property (Annamma et al., 2016). Smartness becomes a cultural currency in school settings, a currency that is racialized and more accessible to White students: "the developing of an identity as either 'smart' or 'not-so smart' is to have very real material consequences vis-à-vis one's access a sense of entitlement (or not) to opportunities, privileges and myriad forms of cultural capital—to smartness as property" (Leonardo & Broderick, 2011, p. 2227).

Kelly was "smart" but she wasn't "good." She described how she was constantly made to feel like "a problem" and was "treated horribly" by teachers. Her body was in constant non-compliance of expected school norms. She did not sit, talked too much, and did not listen. Hatt (2011) defined "goodness" in a school context as "listening to authority connected appropriate behavior and one's ability to become and maintain a docile body" (p. 15). Kelly's resistance to these normed expectations were read through a gendered lens of expectation. Kelly and her mother recounted the ways that Kelly immediately became a "gender outlaw" (Bornstein, 2016) when her gymnastics group became sex-segregated. Kelly's constant movements, inability to wait in line, and need to talk with others only *became* a problem when girls and boys were expected to behave in different ways. Kelly's mother explained, "All you have to do is move her from the girls' group to the boys' group. And she'll be fine." Kelly fell outside of the gendered expectations of a "good girl," but was able to maintain access to mainstream school environments because of her "smartness."

Jordyn and Zula were read very differently in relation to gendered and racialized constructions of goodness and smartness. As a young child, Zula, a White girl, was not read as "good" or as "smart." Zula did not develop language until much older and she struggled to maintain regulation in group environments. She often became overwhelmed and screamed or

"tantrumed." During group lessons, Zula was in constant motion and her mother described her as "difficult to manage." Zula's more pronounced disabilities at a young age positioned her as an undesirable student. She was not read as "smart" or "good" (Leonardo & Broderick, 2011). As Zula aged and as she developed more communication skills which decreased her frustration, she was able to fit into more normative expectations of school behavior. Once she matriculated into elementary school, Zula was never again actively pushed out or asked to leave any schooling spaces.

Jordyn, a Black girl, did not present with the regulation challenges that Kelly and Zula did as young children. Her mother Ada described Jordyn as "easy-going" as a child. But when Jordyn began to lose language at the age of 18 months, Ada was convinced her daughter was autistic. Above, I described the ways in which Jordyn's social behavior was read as proof that she was not autistic. For the very reasons that Jordyn was not believed to be autistic as a young child, "polite, social, quiet, empathic" led her to be viewed as a "good girl." Jordyn's mother explained that Jordyn did not fit the male "model of autism," a model based on autistic boys.

While Jordyn was read as "good," she was not read as "smart." Throughout her life, diagnosticians challenged her autistic identity and instead suggested she was "just intellectually disabled." A recent study found that a disproportionate number of Black autistic children are also diagnosed as having intellectual disabilities (Constantino et al., 2020). Even after the researchers accounted for access to healthcare and socioeconomic status, Black children were disproportionally given an intellectual disability diagnosis: "This raises the possibility that African American children with autism may be disproportionally assumed to have intellectual disabilities and diagnosed as such without adequate psychometric confirmation" (Constantino et al., 2020, p. 6). As Jordyn aged, she began to lose her "good girl" status. In elementary school

when she would not engage in expected activities for food rewards or when she engaged in independent thinking rather than follow the teacher's requests, she was read as "non-compliant." Researchers have documented the ways that Black girls' behavior is more severely scrutinized in schools as compared to their White peers (Hines-Datiri & Carter-Andrews, 2017).

Zula and Jordyn were both asked to leave classrooms and programs because they were described as not being "a good fit." For Zula, this occurred early in her life in a toddler program, a toddler music class, and in a private kindergarten Catholic school. Later in her school life, she was tracked into more restrictive special education classrooms because her skill level was viewed as "too low" for the more academic classrooms. Jordyn was asked to leave school programs because she was described as not "a good fit." In both cases, fitness was defined by their individual proximity to normative expectations. Zula failed the fitness test because of her failure to be deemed "smart enough." Jordyn failed for being read as both not "smart enough" and not "good enough." Kelly's Whiteness and her "smartness" protected her from this particular act of exclusion.

Interdependence

Throughout my participants' narratives, the importance of interdependent support networks emerged. Disability activists and Disability Studies (DS) scholars have long challenged binary conceptions of dependence and independence (Kafer, 2013; McRuer, 2006). They have argued that the notion of independence, the idea that an individual can exist without the support of others, is an able-bodied "myth" (Mingus, 2010). Philosopher Erin Manning (2016) explained that independence is the foundation for particular notions of neurotypicality, or non-autistic identities.

> The neurotypical is the very backbone of a concept of individuality that is absolutely divorced from the idea that relation is actually what our worlds are made of. The neurotypical does not need assistance, does not need accommodation, and certainly does not need facilitation. The neurotypical is independent through and through. (p. 6)

Rather than independence, disability communities and disabled people build interdependent care networks of mutual aid and support or "care webs" (Piepzna-Samarasinha, 2018). One of the most foundational supports for my participants were their relationships with their mothers. Because each mother was able to build a deep "access intimacy" (Mingus, 2017) with her daughter's needs, they were able to advocate for and with their daughters throughout their school lives. As my participants navigated their schooling experience and the transition to adulthood, these women found various disability communities and neurodiverse relationships. Disability community became an essential space of connection and understanding, and through these neurodiverse relationships, these women were able to "imagine disability and disability futures otherwise" (Kafer, 2013).

Mother-Daughter Access Intimacy

Disability justice activist Mia Mingus (2011) described the powerful feeling of "access intimacy":

> Access intimacy is that elusive, hard to describe feeling when someone else "gets" your access needs. The kind of eerie comfort that your disabled self feels with someone on a purely access level. Sometimes it can happen with complete strangers, disabled or not, or sometimes it can be built over years. It could also be the way your body relaxes and opens up with someone when all your access needs are being met. (n.p.)

Each of my participants shared a very special connection with their mothers. In different ways, each mother had a deep sense of "access intimacy" (Mingus, 2017) with their daughter. This sense of intimacy revealed itself in very big ways—through their roles as advocates and when fighting for their daughters' access to educational supports. This intimacy also revealed itself in

small ways, like the way each mother respected and valued their daughters' preferences and communication styles.

While I worked with Kelly, she told a particular story several times. The story took place when Kelly was a toddler. She described the experience of being buckled into a car seat. The experience was horrible for Kelly who felt "trapped" and restricted with the tight belts. Kelly's mother, Judy, was the only person who could convince Kelly to endure the experience. Each time she got into the car, Kelly's mother spent upwards of 10 minutes explaining the importance of the car seat: "She [Judy] was the only one who took the time to logically explain why I had to get in the car seat. No one else had the patience to do that."

Judy's actions created a sense of access intimacy with her daughter. When Judy explained the importance of the car seat, her goal was only about getting Kelly to listen; it was for Kelly to *understand*. She knew her daughter had sound reasoning and if she could help her connect each dot, then Kelly would come to the right choice and sit in her seat. Judy understood that Kelly's refusal was her way of communicating something important, a need from her own nervous system pushing against a feeling of containment. Jumping around the car and refusing to sit was not a rebellion again authority but a resistance to feeling uncomfortable. By calmly and logically explaining why her daughter needed to be in the car seat, Judy acknowledged that Kelly had good reason to feel upset and prioritized her daughter's sensory preferences and communication styles. The car seat example, seemingly small, showed the level of attunement Judy had with her daughter's needs; therefore, when various teachers communicated to Judy that Kelly was defiant, Judy was able to advocate for Kelly's needs by prioritizing her sense making. For Kelly, having her mother understand her and accept Kelly's reality as *real* and *valid* gave her

a deep sense of security and the faith that, although others doubted her, she had in her mother someone who was "on her side" and committed to understanding her perspective.

Patricia, Zula's mother, knew that her daughter was capable of so much more than people expected from her. Being diagnosed at such a young age more than 25 years ago, Patricia had to invent a path for her daughter. Zula's school life consisted of special education programs where her skills and talents were often undervalued. Patricia always knew that Zula's strengths were not being properly valued in her classrooms, so when Zula graduated, Patricia worked hard to help her adult daughter have access to an interdependent life filled with meaningful work, meaningful relationships, and a time and space to pursue her hobbies and passions. Zula's access needs involved having an adult life that was separate from her mother.

> When the rules change, when things change and the child is growing up and has different experiences, you're not there with them. And you hope for the best, but you can't not let them go. They come back hopefully better, not traumatized.

Rather than overly protect Zula, Patricia scaffolded levels of support so that Zula could have access to an interdependent adult life with a priority on her interests. For those interests to flourish, Zula had to have an adulthood that was interdependent with Patricia but also had some separation.

Jordyn's mother, Ada, knew from when she was very young that her daughter was autistic. Despite the pushback she received from diagnosticians, Ada advocated for her daughter to receive the correct diagnosis and the proper supports. When Jordyn was placed in an ABA program, Ada again pushed back against the experts. Ada described as follows:

> All of the experts insisted that Jordyn should be in an ABA kind of program. It was considered the gold standard of autism intervention. I kept telling them that it was not working for her. I watched her regress in the ABA. I kept telling everyone that this is just not how she works.

Although behavioral approaches worked for her autistic son, Ada knew that her daughter needed a more individualized connection in her relationships with teachers and in her educational approach. In behaviorally-oriented programs, Ada was concerned that her daughter's communication styles were not being acknowledged. Ada showed the way she valued and respected her daughter's communication preferences and priorities in little ways like acknowledging the importance of purchasing fish at the grocery story because it was on the grocery list. Because each mother was in tune with their daughter's access needs and autistic communication preferences, they were able to advocate for their daughter's specific needs in large-scale ways.

Advocacy efforts should include a more nuanced understanding of access intimacy. All too often, autistic children are assumed to need similar kinds of supports, whether it be a behavioral intervention or a specific classroom setting. Rather than a one-size-fits-all approach to thinking about educational supports for autistic students, accommodations should be more individualized to individual access needs. These more individualized approaches should include more careful attention to specific communication styles, sensory and processing variations, and interests.

Neurodiverse Relationships

The mother-daughter relationship was a crucial aspect of my participants' lives. Equally important were relationships with other neurodiverse and disabled people. Within these disability communities, there were shared understandings of autistic and neurodiverse communication preferences and expressions. DS scholar Alison Kafer (2013) argued that "disability is experienced in and through relationships; it does not occur in isolation" (p. 8). After years of exclusion and bullying, Kelly first found real connection in elementary school with three other

children, all of whom later went on to identify as part of the neurodiverse spectrum (autistic and ADHD). In this small group, Kelly found a deep sense of connection and belonging. For the first time, she felt that she was understood and did not need to translate herself constantly to others. It was in this peer group that she finally felt at ease, never "too much" or worried she was "annoying." Bridget Rankowski (2017), an autistic woman, described the challenges of constantly "translating" non-autistic communication and social behaviors.

> The social quirks I have of speaking what's on my mind and being completely obvious are not always so charming to me. They can lead to depression, as I sometimes feel isolated in a room full of people who all seem to be speaking in a foreign code. People speak in looks and "you knows" instead of using real words. (p. 25)

With her non-autistic peers, Kelly felt a constant feeling of having to monitor herself or tone herself down.

In high school, Kelly again found deep connection online with larger autistic communities, specifically autistic girls and women. It was through these online networks that she found a sense of identity and felt less alone. In high school, Kelly also found a deep connection with her autistic boyfriend, Cameron, and his autistic father. Rather than being corrected, Cameron and Kelly seemed to understand one another immediately. Kelly explained:

> I started feeling that me and Cameron were the same person. I had this feeling that we were soulmates. We were so similar in the way that we saw the world and the way we would talk and our body language. Now in hindsight, I realize we weren't similar. The things we had in common were autism symptoms.

It was as though Cameron and his father rather than Kelly were plugged into a larger network of autistic advocacy. Currently, Kelly continues to seek out and foster strong peer relationships with other neurodiverse adults. Jean Winegardner (2017) talked about the isolation she felt as someone who was late diagnosed: "the hardest part about growing up undiagnosed was the aloneness. This is different from loneliness" (p. 176). Although Winegardner had friends

growing up, she always struggled with a sense of unbelonging, a feeling that she was never quite understood and had a challenge to communicate meaningfully with non-autistics. Like Kelly, it was not until she connected with other autistics that she had a true sense of connection.

Zula struggled to maintain peer relationships when she was younger due to the transient nature of her schooling experience. Adding to her social challenges was the fact that she was often the only girl in her special education classes. She shared stories of boys being "too loud" when they would curse or become upset and disruptive in class. This led to her not wanting to enter the classroom at all. Then there was the male student who made her feel "too uncomfortable" when he attempted to kiss her without her consent. Most of her school life, Zula did not have deep connections with peers.

Adulthood offered more opportunities for Zula to connect with various disability communities and to create deep relationships. The first significant adult relationship happened with her now-husband, Ben. Ben is also disabled. In Ben, Zula found deep connection, safety, joy, and comfort. The two share common interests of cooking, eating out, going to the movies, watching TV, and spending time with her cats. Ben shows real interest in and care for Zula, and Zula is comfortable sharing her needs and preferences with Ben. The two share an apartment, a life, and a future together. Zula's schedule revolves around connections with various disability groups. She looks forward to her weekly art class and a dinner club with other disabled adults. In the past year since joining Phoebe's House, a social space for autistic women, Zula has made many new friendships with other autistic women. Most often, these friendships are organized around their common interests of cats, art, and cartoons. Zula has even reconnected with a childhood friend through Phoebe's House, a friend she had lost touch with when she had changed schools. The organizational structure of the special education system made it so that

Zula was further isolated from creating lasting peer relationships. In addition, the way in which students were sorted due to their disability labels meant that Zula was consistently the only girl and rarely had the opportunity to make other female friendships. It was only after she left school that Zula was able to find friendship and love in a variety of different disability communities, specifically connections with other autistic women.

Jordyn's connection to neurodiverse relationships is a bit different from those of Zula and Kelly. Jordyn seems to have much closer relationships with her immediate family rather than forming peer relationships in school or now in adult programming for disabled adults. Like Zula, Jordyn was typically the only or one of the only girls in her class. Through her collage work, it was clear that Jordyn showed a particular interest in other girls and often highlighted girls in her selection of photographs; however, while in school, Jordyn did not seem to make particularly strong connections with other classmates. As an adult, Jordyn enjoys some of the participants in her program, but Ada described how Jordyn is resistant to connecting with these participants outside of program hours.

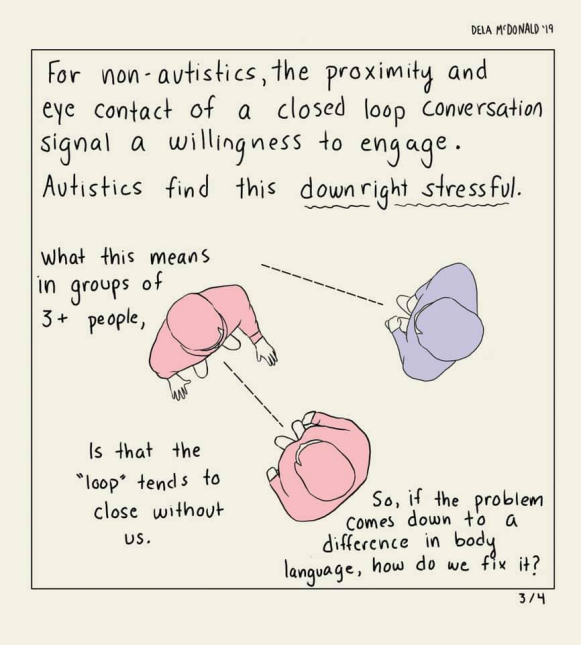
For Jordyn, her closest peer relationship is with her autistic brother, Brandon. The two live together and lead very different lives, but they find ways to connect over family dinners in the kitchen, grocery shopping together, and going on outings to pick up various home items at Target. Throughout Jordyn's room are pictures of Brandon from their youth and photographs from a family trip to Disney World or a dolphin watching boat trip while vacationing at the beach. In the series of photographs that Jordyn sent me, Brandon was featured in several of them, all photographs from when the siblings were younger. Each photograph shows the siblings smiling together. There is an obvious intimacy in the sibling relationship, and although the siblings communicate very differently, there is a sense of "shorthand" between the two of them,

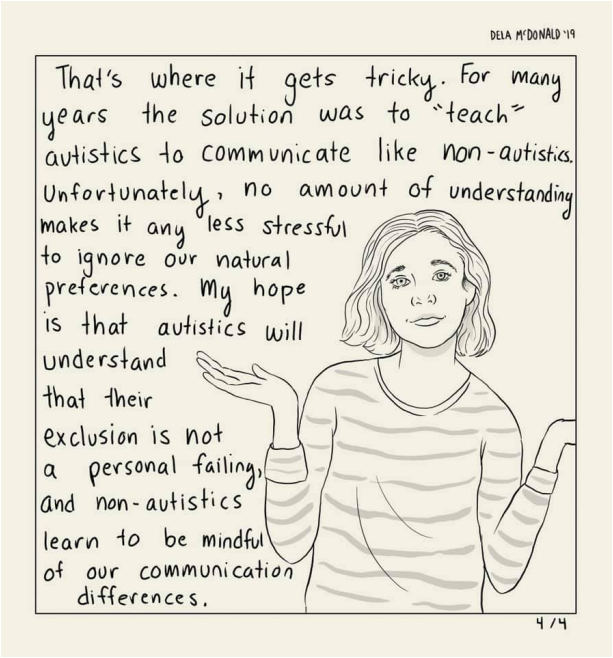
a shared knowingness. Recent research has suggested that within autistic relationships, there are far fewer communication breakdowns (Crompton et al., 2020).

All too often, there is an emphasis on the ways in which autistics "lack" social skills or "struggle" with peer relationships, but when my participants were able to connect with other neurodiverse peers, their relationships flourished because their particular neurodiverse communication styles and access intimacy (Mingus, 2011) were more readily understood. Autistic activist and artist Dela McDonald (2019) illustrated in a four-part graphic series some of the ways in which autistics are left out of conversations with non-autistics (Figure 59). She described that autistics may prefer an "open-loop" conversation style, where an individual positions their body in a way that is more open to the room rather than directly facing their conversation partner. Non-autistics prefer a "closed-loop" conversation style, where close body proximity and shared eye contact are privileged.

Figure 59. *Open- vs. Closed-Loop Conversations: A Four-Part Series*

Figure 59 (continued)





McDonald (2019) ended the series by explaining that the onus should not be placed on autistics to adapt to non-autistic preferences, but that perhaps non-autistics should broaden their understanding of communication preferences of neurodiverse people. Similarly, Amy Sequenzia (2011), an autistic writer who types to communicate, shared her perspective on communicating with non-autistics in an excerpt of her poem:

> Because my way of processing
> Feelings, thoughts, words, emotions
> Is different.
> But they still are
> Feelings, thoughts, emotions and words.
> I promise to be patient with you too
> Because your way of communicating
> Is also very strange to me. (n.p.)

Autistic communication is different—not less than; rather than placing the burden on autistic people to perform constantly and translate their natural ways of expression to fit more

comfortably with non-autistic communication patterns, perhaps non-autistics can learn how to be better communication partners within their neurodiverse relationships.

Teachers as Arbiters of Trauma and Architects of Possibility

Schools as places for trauma and inequity for many students, especially for students with disabilities, is largely documented (Annamma, 2017; Harris, 2019; Kozol, 2012; Shalaby, 2017; Valle & Connor, 2010). However, what emerged in the participants' stories were also small ways that individual teachers took a strengths-based approach towards these women and challenged the notion that they were a problem. The participants and their mothers explained the ways in which various school settings and teachers either took up a deficit or strengths-based approach towards themselves and their daughters. Kelly described these teachers as "flexible or inflexible"; in Jordyn's chapter, Ada described these teachers as "believers and non-believers"; and in Zula's chapter, Patricia described teachers as "having or not having expectations." I briefly outline the ways that these three women experienced exclusions and, at times, violence in schools at the hands of teachers. I then suggest that teachers who had a strengths-based approach towards these participants were engaging in an aspect of neurodiverse culturally responsive pedagogy.

Teachers as Deputies of Violence and Exclusion

Each of my participants shared an experience from their schooling lives that involved violence or bullying perpetuated by their own teachers. Kelly experienced direct violence from her preschool teacher. When Kelly consistently took "too long to finish snack," her preschool teacher became angry and engaged the toddler in a tug-of-war with Kelly's yogurt cup. The end result was that Kelly's teacher dislocated Kelly's elbow, leading her to have to seek out medical attention. No disciplinary action /was taken against the teacher for her violence. Kelly was

routinely isolated from her peers because her body movements did not fit within the expectations of normal classroom behavior. She struggled to sit still and, therefore, was routinely removed from the classroom or kept in during recess.

Throughout her schooling years, Zula was often viewed as a student who did not meet her teacher's expectations. As a young toddler, Zula was asked to leave programs and was actively excluded from school-wide events because her behavior was seen as a negative model for "the other children." In middle school, Zula was actively targeted by a teacher in middle school. Ms. Courtney played particularly close attention to Zula. Her interest was under the guise of support; however, she routinely criticized Zula's weight, her appearance, and her social skills. She repeatedly critiqued Zula during class in front of her classmates, and when Zula would not comply with Miss Courtney's expectations, she took away school privileges.

Jordyn was asked to leave classroom settings and school programs because she was viewed as "not a good fit." Jordyn was routinely reprimanded for displaying "unfunctional" behaviors in her various school settings. These behaviors included showing empathy and concern for her classmates, refusing to engage in an unwanted activity, or not removing her noise-cancelling headphones. In one of her school programs, she was physically harmed via lead poisoning when the lining of the school's pool leaked dangerously high levels of lead into the swimming pool.

The deficit framings of these women were enacted across a wide range of school settings and were not bound by place-based programming. Kelly experienced exclusion and trauma in public general education settings, Zula experienced bullying at the hands of her teacher in special education public schools, and Jordyn experienced deficit orientations from teachers in special education private school settings. Across each of these settings, there were also moments where

individual teachers took a strengths-based approach towards each of the participants and, in so doing, were enacting small moments of neurodiverse culturally responsive pedagogy.

Neurodiverse Culturally Responsive Pedagogy

Culturally responsive pedagogy (CRP) asks teachers to prioritize the cultural contexts, familial strengths, and high expectations as central aspects of equity instruction (Ladson-Billings, 1994). This work came from a need to address systemic racial inequity in school systems and classroom practices which centered Whiteness as neutral. In this regard, students of color, their families, and their cultural expressions were positioned in deficit orientations (Gay 2010; Ladson-Billings, 2009; Milner, 2011). All too often in discussions of diversity and culturally responsive pedagogy, disability culture is not included as a part of the discussion (Connor et al., 2008; Siebers, 2016). Disability Studies scholars and activists understand disability as an aspect of identity that comes from a unique and specific disability culture (Brown, 2001; Kafer, 2013; Linton; 1998; Oliver, 1996; Wade, 1992; Wong, 2002). When disability is not framed as an aspect of culture and diversity, disabled student knowledges are not being recognized as an important space of knowledge production. While CRP scholars are examining the important intersections of English learning (Tran et al., 2018) as well as the experiences of students of color in special education (Cramer et al., 2014), neurodiversity and autistic cultural expressions are underexplored aspects of CRP.

CRP-informed practices center student interests and cultural expressions as important spaces for pedagogical inquiry. Pedagogy specifically incorporates culturally specific ways of knowing in order to increase student engagement and a sense of belonging (Brockenbrough, 2016; Gay 2010; Ladson-Billings, 2009; Milner, 2011). Hammond (2015) described a common misconception: “Culturally responsive teaching is less about racial pride as a motivator and more

about mimicking students' cultural learning styles and tools" (n.p.). By privileging students' knowledge production styles, classrooms can become more inclusive environments for students of color. Neurodiversity and the experience and knowledge productions of neurodiverse people represent an important cultural space with a unique identity (Baker, 2011; Murray, 2010) that is often ignored in classrooms. CRP works to disrupt the centering of Whiteness as the "norm" in classrooms and, as discussed earlier in the chapter, DisCrit reminds us of the ways that racism and ableism are "normalizing processes that are interconnected and collusive" (Annamma et al., 2016, p. 14). How can aspects of CRP be applied to disability culture and, more specifically, neurodiverse students so that their knowledge productions and neurodiverse needs are an important part of the classroom pedagogy?

Each of my participants had moments of true connection in school settings. Often, these moments of belonging came from an individual action of an individual teacher. These small moments had ripple effects on the outcomes of these women. There were two distinct moments from Kelly's early school life, where teachers centered Kelly's interests and particular preferences in their classroom pedagogy and classroom expectations. The first occurred in Kelly's preschool. Due to noise sensitivity, Kelly was afraid to flush the toilet. While her head teacher took a forceful approach and forced Kelly's hand to flush the toilet, a college-aged assistant teacher instead used Kelly's interests in birds as the central organizing strategy to teach her to flush the toilet with her foot—a strategy that Kelly still uses to this day due to auditory sensitivity. Rather than challenge her reality or frame her fantasy thinking as a deficit, this teacher embraced Kelly's specific interests and knowledge production as assets.

The second moment of cultural competency occurred in Kindergarten when Kelly's teacher allowed her to move freely around the classroom space. Kelly explained:

> My best teacher was my kindergarten teacher because she didn't really care what I did. Like if I was in a group, I would often put my head down, put my head on my knees, look down or away or rock back and forth (demonstrates it). My teacher didn't really care because she would ask me what she was talking about and I would repeat it. I was listening so she didn't really care if I was seated like eyes forward, hands quiet, sitting up (demonstrates it). She didn't care how "paying attention looked."

Rather than reproduce the expectations of normative school behavior, this teacher was able to take a more flexible and student-centered approach towards Kelly. Instead of adapting a one-size-fits-all approach to teaching which favors the White, non-disabled learner (Annamma, 2017), her Kindergarten teacher was able to individualize expectations for Kelly based on what her needs were. Although Kelly was not diagnosed at the time, her need for movement was an expression of her neurodiverse identity, a cultural expression (Gobbo & Shmulsky, 2016). As an adult, she now understands her need for movement as a unique aspect of her nervous system, and that by moving or stimming, she is more available for conversation and learning. When her teacher allowed her to move in a way that she needed, the teacher was embracing a neurodiverse way of being in her classroom.

For Jordyn and for Zula, the teachers who had the most impact on their lives were teachers who held high expectations for them and embraced their interests and strengths. Patricia, Zula's mother, mentioned that it was not until high school when a particular teacher saw Zula's skills. Patricia explained that "Ms. Theresa gave her a chance. She was nurturing but had high expectations for Zula." Brockenbrough (2016) noted that an important aspect of CRP is the combination of care and high expectations of students to counter against deficit-oriented narratives. Ms. Theresa advocated for Zula to be placed in the hybrid job training class housed in a university mailroom rather than remain in the special education classroom that did not have any job skills expectations. Ms. Theresa's faith in Zula and her knowledge of Zula's strengths led to her positive experiences in the mailroom, which in turn led to positive work experiences in

her adult life. The job tasks of the mailroom fit with Zula's strengths in visual memory and required a low demand of her verbal skills. Zula takes great pride in her current job at a thrift shop, a job she was able to acquire because of her mailroom experience.

Jordyn's mother, Ada, described several teachers who were "believers," meaning that they had a sense of Jordyn's strengths. There were several teachers at Oakdale Academy that Ada described as seeing "Jordyn's spark" and helping her to find her "inner diva." Teachers worked to establish trusting relationships with Jordyn by learning about her interests and helping to support her sensory sensitivities. In past programs, Jordyn's refusal to engage in compliance-based learning activities was understood as an expression of defiance, whereas at Oakdale, Jordyn's reluctance to participate was viewed as a form of communication about her needs (Figure 61). For Jordyn, refusal was a powerful form of dissent, an important part of her cultural expression that was going unacknowledged. When she entered Oakdale, Jordyn wore noise-cancelling headphones. Rather than ask her to remove them, teachers and therapists worked to support Jordyn's sensory profile so that she was less sensitive to sound and less easily overwhelmed. As Jordyn's needs were met and her interests were prioritized, she felt safe and no longer had the need for the headphones as a source of protection. She chose to remove them when she felt safe and her needs were respected.

Dela McDonald (2020), an autistic artist, activist, and parent of a young autistic girl, illustrated the importance of attending to the sensory needs of her daughter Ru and understanding behavior as a part of communication. In a four-part illustration, McDonald showed how her daughter engaged a range of sensory experiences and explained that only when Ru feels safe and her sensory needs are met, learning can occur (Figure 60). The second image is also the work of Dela McDonald (2019) and is one cell from a larger drawing (Figure 61).

Figure 60. *This Is Where Learning Happens*

Figure 61. *Behavior Is Communication*

Figure 60 shows a four-part panel by artist Dela McDonald. It depicts her young autistic daughter Ru happily engaged in various sensory-based learning activities, including jumping on a trampoline, swinging, and playing large colorful chimes. The last frame of the image reads, "We learn when we feel SAFE and SOCIAL. Being forced to comply and having our needs ignored teaches us to avoid pain. That's not growth." Figure 61 shows one cell of a larger cartoon, with McDonald's daughter Ru looking distressed and a thought bubble reading, "I have an unmet need." The text reads, "There are so many ways to get your point across. Not to mention the fact that…BEHAVIOR IS A FORM OF COMMUNICATION!"

In individual moments, teachers responded to students' strengths, interests, and meaning making. Autistic researcher Dr. Wenn B. Lawson (2018) created the infographic shown below to illustrate the importance of incorporating interests and passions into the education of autistic students (Figure 62). Lawson explained that by incorporating the interests of autistic students,

teachers are "turning on" the availability for student learning. When teachers and schools center autistic interests, plan for their sensory needs, and accommodate for a range of communication preferences, teachers are engaging in an expression of neurodiverse cultural competency.

Figure 62. *Nothing About Me Without Me: My Passionate Mind*

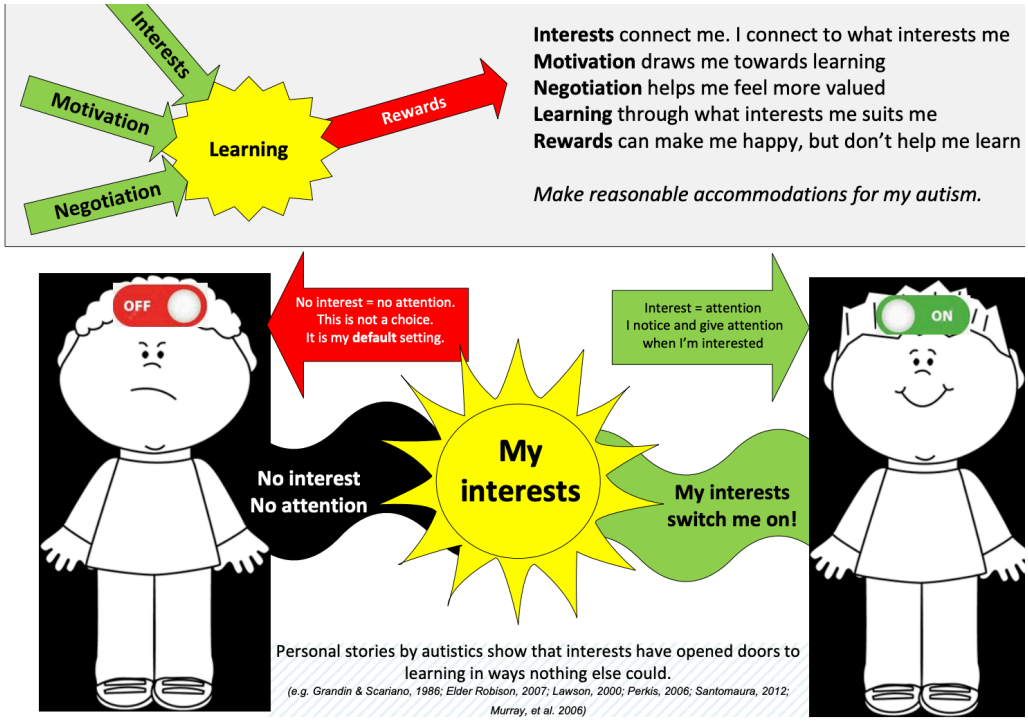


Figure 62 illustrates the importance of incorporating autistic interests as an essential aspect of learning. The top part of the image discusses the ways in which interests are a gateway to connection and motivation. The graphic below is a cartoon drawing of an autistic child. The image shows that the child's brain is "on" when their interests are incorporated, but "off" when learning does not take interests into account. It is important to note that the image of the "autistic child" is portrayed as a White or racially neutral boy, again speaking to the ubiquity of Whiteness and maleness associated with autism.

Autistic culture and neurodiverse communication styles and interests must be acknowledged as an important aspects of student identity. Autistic identities produced unique

and powerful autistic knowledges that are either going undervalued or becoming the targets of classroom disciplinary policies. Individual teachers can push against these silencing practices by embracing their students' neurodiverse communications styles in their classrooms. For these women, part of their communication matrix included movement, stimming, and refusal. When teachers respected and responded to these communication expressions, they were holding important space for neurodiverse knowledge expression and enacting inclusive practices. Naraian (2017) explained that conversations regarding inclusive practices should be more expansive than simply the *where* of classrooms and individual teachers can "make strategic decisions to foster inclusive practices in the classroom" (p. 7). Despite the larger structures of schooling, the actions of individual teachers making small choices to privilege these women's knowledge productions had long-lasting and meaningful impacts on these women's lives.

Implications for Practice and Policy

Autistic women have long been left out of research studies. This study focused specifically on autistic women's experiences. My participants' narratives revealed important, long-ignored implications that have impacts on schooling and policy, both for autistic women and the larger neurodiverse student body.

Much of the current conversation surrounding inclusive education gets stuck in a "place-based" framework. Inclusive practices revolve around the *where* of schooling. What classroom is a child placed in? What peers are they surrounded by? Place-based conversations are meaningful as inclusive vs. restricted settings can have long-lasting effects on student outcome and access. For example, students who are placed in special education classrooms may not have access to a high school diploma (Ferri & Connor, 2010). However, conversations around inclusive education

for autistic students needs to move past binary definitions of inclusion and exclusion and interrogate what equity and access can look like across a variety of different settings.

Prioritizing neurodiverse ways of knowing, centering autistic interests as essential aspects of curriculum development, allowing all students to move more freely in classroom spaces to give their bodies the input they need, allows for increased equity, regardless of school placements. In centering autistic interests, teachers need to be more attuned to the particular interests of autistic girls and offer more curriculum and programming with those interests in mind. Often, these interests include art and music-based activities and a focus on nature and animals rather than the more male-oriented autistic interests of transportation and technology (Attwood & Grandin, 2006; Ballou et al., 2017; Mandy et al., 2012).

There is a push-pull relationship regarding children being labeled as autistic or receiving a disability diagnosis in general. When children receive a disability label, they are more likely to be placed in separate classrooms and may not have access to the same diploma as their non-disabled peers; this is especially true for autistic children of color (Harry & Klingner, 2014; Losen & Orfield, 2002). However, without a diagnosis, children may struggle to succeed in class or with peer relationships without the necessary supports and accommodations. The larger issue underlying this tension is the stigma of disability. For autistic girls to flourish in school settings, there needs to be a cultural shift around disability in general. Autism, similar to other disability categories, should be framed as an expression of identity. School curricula should incorporate disability history as an aspect of American history. Disability activist and artist Cheryl Marie Wade (1992) described that claiming a disability culture involves acts of reclamation: “It’s finding a history, naming and claiming ancestors, heroes. As ‘invisibles,’ our history is hidden from us, our heroes buried in the pages unnamed, unrecognized. Disability culture is about

naming, about recognizing" (p. 15). In discussions of classroom discussions and curriculum units that address diversity, disability should be included as an aspect of diversity.

Neurodiverse students need more social support systems in schools. Just as students have found safe havens in LGBTQIA youth groups led by a Queer teacher or ally, schools should create safe peer support spaces for students who identify as neurodiverse or disabled. Bullying is a big part of many autistic children's lives, and while there has been explicit discussions in schools around bullying, there has not been as much support in helping students find deep connection and community. Each of my participants found true connections with other neurodiverse or disabled people. Campbell (2018), a late diagnosed autistic woman, referred to this as "finding your tribe" (p. 21). Schools should take a more active role in helping these students find one another so that school can be a space for neurodiverse connection, specifically facilitating connection among autistic girls and young women. The biggest protection from bullying is having a strong support network of peers.

Teachers need more training on how to support neurodiverse students in their classrooms. These supports need to extend past behavior management techniques and instead include ways that teachers can create more sensory-friendly classrooms, specific trainings for more visual supports, and a deeper understanding of a wider range of communication tools. Autistic adults need to forefront these conversations and take a more active role in school policy and procedures that impact the school lives of autistic students.

Specific to autistic girls, there needs to be a more robust understanding of how autistic girls express themselves differently as compared to their male peers. Teachers are often in a position to refer students for evaluations, but teachers are not always aware of the way in which autistic girls express themselves differently than autistic boys. Explicit trainings, ideally

spearheaded from neurodiverse women themselves, should be accessible to teachers so that they can be more attuned to their students who may be struggling with either the wrong diagnosis or no diagnosis at all. Clinicians need to be more aware of the ableist biases embedded in the diagnostic process, and more sophisticated and flexible diagnostic tools need to be created that better reflect the wider autism community.

Implications for Theory

Conversations around autistic students and schooling are often fixed in binary constructions of special vs. general education. Instead, what this project suggests is that teachers can make inclusive choices in micro ways, regardless of the larger school setting. Embracing a messier construction of inclusive pedagogy and neurodiverse cultural competency opens pathways of possibilities between teachers and students.

A key organizing principle in Disability Studies and Disability Studies in Education (DSE) is the notion of presuming competence, the idea that disabled individuals have the ability to think, learn, and understand (Biklen & Burke, 2007). This concept, however, is often conceived as a binary construct. A teacher is often described as "presuming competence" or having a "deficit perspective" towards students. Instead, what this project illustrates is that this process is much messier and more fluid. Presuming competence is a process of ongoing reflection, reevaluation, and interrogation with larger systems of ableism, racism, and gender.

Additionally, teachers and parents may not understand their disabled children and students as "capable" if they are not able to embrace different ways of being and knowing in the world. In the context of this project, presuming competence requires a sense of "access intimacy" (Mingus, 2017) towards their students so that teachers can flexibly respond to the shifting access needs of students. Teachers who do not have an understanding of a student's neurodiverse

talents, interests, and passions will struggle to see their full capacity, and this will restrict the teacher's ability to see their student's full range of potential.

There is great generative potential in thinking about intersections of culturally responsive pedagogy, DS, and DSE. When viewing disability as an important cultural space, inclusive practices can be reimagined to center neurodiverse ways of knowing. In this framework, stimming, silence, and hobbies and interests are understood as important pathways of meaning making and knowledge production for autistic students. Rather than autistic students simply "fitting in" to classroom spaces, their cultural identities should be planned for in advance. Steven Brown (2001), co-founder of the Institute on Disability Culture, explained that for far too long, it has been the burden of disabled people to fit into non-disabled culture.

> It is absolutely not our job it fit into mainstream society. Rather it is our destiny to demonstrate to mainstream society that it is to their benefit to figure out that we come attached to our wheelchairs; our ventilators; our canes; our hearing aids; etc. and to receive the benefit of our knowledge and experience mainstream society needs to figure not how we fit in, but how we can be of benefit exactly the way we are. (n.p.)

When classrooms adapt more flexible understandings of classroom participation, including the need to move, the need to refuse, and the need to incorporate interests and joy as an expected part of the classroom curricula, all students can benefit.

Implications for Research

Research studies that have focused on autistics have rarely included autistic perspectives (Glassford et al., 2016; Halladay et al., 2015; Mandy et al., 2012). Additionally, research approaches have long privileged verbal expression as the main avenue to learn people's stories and to share knowledge. For autistic knowledges to be incorporated fully, research approaches need to include a wider range of communicative expressions and multimodal approaches.

Conducting Research with Autistic Coauthors

Research *about* autistic students' needs to be approached *with* autistic people and their care networks. In approaching this dissertation research, I wanted to forefront the experiences of autistic people and privilege their modes of expression; however, there were restrictions in terms of the dissertation process being designed to be single-authored. Moving forward, I would want to further push the participatory nature of research projects to incorporate autistic advocates, scholars, and family members as co-authors of the articles from their inception. Research traditions such as Participatory Action Research (PAR) offer ways to think about how research questions, methodology, data collection, analysis, and writing can be a collaborative process between researchers and community members (Dyrness, 2008). Rather than a prescribed set of methodological practices, PAR is more of a research commitment, "to observe and problematize community concerns in a cyclical process of planning, action, observation and reflection" (McTaggart, 1994, p. 315). However, many of the PAR project designs privilege traditional ways of communicating and methods; while democratic in orientation, they also hinge on verbal participation that may not be inclusive of a wide range of autistic knowledge productions and participation. There needs to be a more expansive understanding of the concept of participation.

The research approaches that I employed in this dissertation allowed for multiple ways of expression and also prioritized relationship building as a key component of the research model. All of this took significant amounts of time. Moving forward, research approaches that are aimed at incorporating the perspectives of disabled people in meaningful ways need to embrace a concept of "crip time" in their research methodologies (Kafer, 2013; Samuels, 2017). Incorporating flexible notions of "crip time" means restructuring timetables to account for accessibility challenges, schedule changes, and time for relationship building and prioritizing

interests and moments of shared joy. Rather than adapt research projects after the fact, multimodality should be a built-in approach from the beginning of a research project. DS researchers and disabled scholars Prince and Kerschbaum (2016) explained the importance of *planning for* rather than *adapting to* disability.

> Disability crips methodology. In other words, when disability is assumed to be an important part of the qualitative interview situation (rather than something external that "enters" the situation and then must be accommodated or compensated for), the interview's normative framework is both exposed and challenged. (p. 20)

Multimodal Approach to the "Interview"

One of my methodological goals in this research project was to create multimodal ways with which my participants could share their knowledge. During the proposal process, I had imagined that I would incorporate self-portraits and photo elicitation as a way to learn about participants' self-views. I looked to researchers who had done a "draw and write" approach (MacGregor et al., 1998; Mitchell et al., 2011; Ozden, 2009), where the researcher would ask a participant a prompt (Can you draw a self-portrait?). I had planned to engage the participant in a verbal or written response to the drawing. I had planned to audio-record any verbal conversation, or if a participant preferred not to draw, offer a photo elicitation option of stock photos that represented various gender-presenting individuals and engaged the participant in questions around self-identification (Teachman & Gibson, 2018).

What I found was that this particular style of multimodal "interviewing" was simply very limited in its ability to embrace autistic communication styles. When I attempted to use these kinds of approaches with Jordyn and Zula, they did not work. Both women expressed disinterest by simply ignoring these attempts or asking to do something else. Kelly requested to not engage in a portrait activity because she described it as feeling like an "assignment." In approaching the

multimodal interview in this way, I was still adhering to a particular understanding of communication that fell within a non-autistic understanding of representation. Rather than draw a self-portrait, Zula wanted to draw SpongeBob; rather than sort pictures into categories, Jordyn wanted to create collages and experiment with various glue textures. Rather than being assigned a self-portrait, Kelly enjoyed sharing her memories through stories and exploring old comic books from her youth. Multimodal interviewing therefore needs to do more than just offer alternative options; it needs to rethink the way that we learn people's stories.

What would research look like that prioritizes what philosopher Erin Manning (2016) described as "autistic perception"?

> Autistic perception is the opening, in perception, to the uncategorized, to the unclassified. This opening, which is how many autistics describe their experience of the world, makes it initially difficult to parse the field of experience. Rather than seeing the parts abstracted from the whole, autistic perception is alive with tendings that create ecologies before they coalesce into form. There is here as yet no hierarchical differentiation, for instance, between color, sound, light, between human and nonhuman, between what connects to the body and what connects to the world. (p. 14)

In writing up this study, I incorporated drawings and photographs from and of my participants as a way to highlight both their particular artistic expressions as well as to privilege their sense making. I contextualized these photographs with descriptions of movements, preferences, and gestures made in the spaces between. I hope that those descriptions captured some of the complexity of my participants' meaning making.

In future projects, I want to explore how multimodality could be incorporated into a wider range of the research process. For example, how could my findings be represented in an infographic or a graphic novel? How could member checks be done through pictures or video? In what ways can a written academic article also be more accessible to tech readers? Is there a way to translate an academic piece and offer a plain language version in order to be accessible to a

wider range of audiences? Rather than a published article, perhaps this kind of research would involve more of an exhibit—a space to walk through and hear various interviews, sounds; a place to experiment with glue textures; a room in which to sit and watch a preferred SpongeBob episode; to see the images that Jordyn and Zula created; to touch the dried edges that remain from the glue. Is there a way to share findings that attend to a more diverse expression of "autistic perceptions" (Manning, 2016)?

Directions for Future Research

I believe this research project in a small way addressed a much-needed area of continued focus. More research needs to commit deeply to exploring the experiences of the autistic and neurodiverse community, especially members who represent gender and racial minorities which includes women, gender-non-conforming people, and participants from various ethnic and racial categories. Because this project was a narrative inquiry, I responded directly to what came from my participants. Because two of the three participants were White women, there was a limitation regarding how this project fits into a larger conversation about equity, access, and representation of autistics of color. This is a much-needed area of focus for future research studies and an area of need that has been identified from autistic community members. Specifically, there has not been enough focus on assistive technology and how accessible/inaccessible alternative communication systems have been to autistic minorities and their families.

Additionally, there has been not enough research on how to support neurodiverse students in their peer relationships. There are copious amounts of positivist research that focuses on measuring the deficits of autistic children and their social relationships. Imbedded in this research is the assumption that the intended "friend" is a non-neurotypical friend. Therefore, interventions and research have focused on how to support autistic children to adapt to the

communication and play styles of non-autistics. The autistic child must change in order to establish friendships. What I find more necessary is examining what strengths already exist in neurodiverse friendships and play patterns and how teachers and families can support existing neurodiverse friendship patterns. Additionally, in what ways can we help non-autistic children and family members adapt to autistic communication styles?

Lastly, research criteria for studies that examine autistic experiences need to be redefined to incorporate a wider range of the autism community. Currently, a majority of large-scale studies only permit participants who have a professional diagnosis. In terms of validity, these criteria specifications make sense; however, there are serious concerns regarding representation using this particular definition. The *DSM-5* acknowledges that the current diagnostic criteria do not fully capture the "subtler manifestations of social and communication difficulties of girls and women" (APA, 2013). Additionally, access to professional diagnostic services is extremely expensive without access to reliable healthcare. Current research names access to healthcare as the biggest factor in the diagnostic age gaps for Black and Latino children, as compared to their White autistic peers. Research studies need to expand their participant pools to include self-identified autistics so that research can represent a wider range of the autistic community.

A narrative inquiry project that is deeply rooted in an emancipatory DS framework allowed for a messy and complex telling of three women's school stories. These women shared their schooling experiences in a variety of different ways. The research approaches needed to be relational, flexible, multimodal, and patient in order to attend to the beautiful ways that these women narrated their lives. This project is just the beginning. There needs to be more and varied ways that autistic women can be moved to the center of narratives around autism and autistic identity. For far too long, they have been silenced, ignored, and erased from research, schools,

and popular imaginings of autistic identities. For schooling spaces to be inclusive, safe, and welcoming, autistic women need to be part of the conversation on how to better adapt and center their experiences and needs.

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Appendix A

Interview Protocols

Interview Protocols with Participants (Autistic Women)

Establishing consent and ethical conditions of interview:

Hello my name is Rae Leeper. This is (say date) at (time). I am interviewing (state name of participant) at (state location). Can you please introduce yourself.

Can you tell me about your elementary school experience?

In the narrative life story phase of the interview process (Kim, 2016) the interviewer does not interrupt and instead engages in active listening. After some time they may ask for expansion of the question using a two sentence format (Wergref's (2011);

"We've talked allot about what school was like for you, especially your relationships with teachers. Can you tell me more about peer relationships?"

Other open-ended questions may include:

- How did you feel when you were in school? Where did you feel most comfortable? Least comfortable? Where did you spend the most amount of time in school? Tell me about your preferred academic subject areas? Least preferred?
- Did you receive specific therapeutic supports in school? What do you remember about those supports? What were you told about why you needed this? What did you find the most helpful? The least helpful? Did you remember peer responses to these therapeutic supports?
- Can you tell me a story about the people in your school? Is there a teacher that stood out in your memory and can you tell me a story about that teacher? Is there a teacher that you

found particularly helpful or supportive? Is there a teacher that you found particularly difficult or unsupportive? Can you tell me more about those teachers?

- Can you tell me about your most important friendships? Who made you feel the most understood? Were there peers that made you feel excluded? Can you tell me a story about those experiences? Did you feel alike or dissimilar to your peers? Did gender play a role in your friendships? Why? Where did you friendships occur? What kids of activities did you do together? Where? What kind of social situations did you find the most rewarding? The least rewarding? Can you tell me a story about those experiences?

Interview Protocols with Families

Establishing consent and ethical conditions of interview:

Hello my name is Rae Leeper. This is (say date) at (time). I am interviewing (state name of participant) at (state location). Can you please introduce yourself and state your relationship with (participant).

Can you tell me about (participant) as a child?

In the narrative life story phase of the interview process (Kim, 2016) the interviewer does not interrupt and instead engages in active listening. After some time they may ask for expansion of the question using a two sentence format (Wergref's (2011). *For example if a parent was explaining the history of their child's therapeutic interventions I may say,*

"We've talked allot about what school was like for (participant), especially kinds of programs and therapies they received. Can you tell me more about what impact those services had on them?"

Other open-ended interview questions could include:

- Tell me about (participant's) diagnosis story? How old were they? How did that process go? What led you to pursue a diagnosis? What were your responses to hearing the diagnosis of autism? Did your child's gender play a role in receiving a diagnosis?
- Tell me about a teacher you remember? Was there a teacher that you remember as being particularly supportive? What about a teacher that was not helpful? Can you tell me why that relationship was difficult for your child?
- Tell me about (participant's) childhood friendships? What was your memory of their earliest friendship? Can you explain that friendship? What about their relationships in elementary school? In high school? Were there particularly challenging friendships over the years and how did that play out? What role did gender, if any, play in their friendships?
- Tell me about their transition out of school? What were your hopes and dreams for (participant) as they transitioned to adulthood? What was the preparation for that process? What did your child hope for their adulthood? Are there obstacles that your adult child faces in the adult world? In work opportunities?

Appendix B

Field Notes/Interview

- Interview/conversation session with June-February 2nd, 2017
- Session #3
- In my office-1:1-in a familiar location

	Date: March 1st, 2017	
	Background: June loves the show Drake and Josh- an old Nickelodeon show about two brothers. There are lots of scenes about dating, high school, and themes about gender roles. I chose an episode, "Girl Power" in which Drake's girlfriend beats him in a wrestling match to see if this sparked some conversation about gender roles. Here's part of a conversation of the first ½ of the show. **As we're watching we ate some snacks. I think this helped to make things more casual and made June feel less on the spot.**	
Time	**Descriptive notes**	**Reflective notes**
4:00	I: If you had to choose who to be friends with between Drake and Josh, which one would you choose? J: Josh I: ok. Why? J: He's calm. He's mellow. He's quiet. He likes video games. Yeah. I: So if you were to hang out with Josh. J: This is not for real right? I: Just pretend. J: This is FUUUUUN!	I think this is interesting. Drake is depicted as the kind of "lady's man"- he's the "cool guy"- musical, long hair, lots of girlfriends etc. Josh is the nerdy type who is nervous, has a serious girlfriend and is often the punchline to the joke. I'm curious how June identifies w Jake. Is it that she's not picking up on the more traditional "attractive" qualities of Drake or is it that she identifies more with the Josh character. It's def true that Josh is more similar to the boys that she has a crush on in real life. Does she find Drake offensive?
5:20	I: If you were going to hang out what could you imagine you would do together? J: He works at a movie theater. Maybe I could work with him. Have an employee. Gold vest. It's called the premier. Giving people their popcorn	Again--- I think what I'm trying to understand here is to use the show and the characters to get at her understanding of gender and the different kind of stereotypes of masculinity. Josh is the kind of nerdy sensitive type- a bit overweight and nervous. Drake is the kind of "player" type that has long hair and lots and lots of girlfriends. Its interesting that June is identifying more with Josh. Does she do that because she sees herself as like him or does she see herself more drawn romantically to him?

	and soda and collecting money. It would be fun. I: So Josh is the calmer one. What about Drake? J: No! I: No? J: He's kind of wild, Drake. He can be bossy to Josh. Mean. I: He's wild? J: He's all over the place. He's sits there. He moves. Then he leaves.	Super interesting that her understanding of "wild" is literal physical speed.
6:00	I: There in High School? J: Yeah and Josh has a girlfriend Mindy. I: Ok J: She's good to him. She invites him to dinner at her house and they get along. I: What do you think of their relationship? J: They get along pretty good. Josh loves her. He's always kissing her. He serves her food. He's nice to her. I: How does Josh treat Mindy? J: Mindy treats him the same way. She likes him she loves him. She's nice to him.	It's interesting that she uses external behavior as "proof" of their relationship. These are all things that June can see rather than infer.
8:24	J: I like talking about dating and stuff and like that I have a crush on Daniel. I: How's that going? J: Sometimes I talk to him.	
9:30	*Watch the first few minutes of the episode- Drake and Josh- where each character is talking about dating and having fights with their girlfriend.* *Josh- In my whole life I've only had 1 real girlfriend.* *Drake- In my whole life I've only had like 74 girlfriends.*	

	Together: But the one thing I've learned in dating is-- <u>THE GUYS IN CHARGE!</u> *And then the scene unfolds where both boys end up deeply apologizing to their respective girlfriends and begging for them to forgive them… It was all my fault.*	
11:15	I: What did you think? J: It was strange. They were talking about their girlfriends and how they yelled and apologized. It was confusing. They were saying so many things like they broke up with Mindy… I: They were talking kind of fast. Should we watch a little part of it again? *Play part of the clip again. June says along with the show: THE GUY'S IN CHARGE!*	I wonder how she's interpreting this. There is a switch in the show where the boys say one thing-- THE GUYS IN CHARGE-- but then do another thing-- immediately apologize to their girlfriends and tell them that they are right. I wonder if June gets this turn or if its something that she just doesn't find interesting.
12:37	J: I think that the girls should be in charge and not the boys because the girls are pretty smart and they know what's right and they know the person really well….. That's funny Drake and Josh. That's funny! *Continue to eat and cut up an apple ….. June laughs*	This is really interesting to me. June has a sense of justice and equality of the sexes. She's able to identify the sexism of Drake and Josh but then reinscribes a specific notion of femininity as "more responsible" and perhaps a "more pious".
14:54	J: So anyway back to the Drake… we got distracted by cutting this apple. Laughs I: So what did you think was the most interesting part of the video? J: I was surprised with they said that boys should be in charge. How come they said that? That's not respecting the girls. Ignoring. Wow look at me go. Wow! I: So you don't think they are being respectful of girls? J: And responsible. I: And responsible. Do you think girls are more responsible than boys?	I think it's great that she's the one that brings us back to the topic. It disrupts the dynamic of me kind of "grilling her" which is hard to get away from. Perhaps this is why June doesn't identify or "like" Drake. She sees him as irresponsible.

	J: Yeah. Like Drake I don't think he's responsible. He's bullying Josh. He's not cool. He bosses him around and says - get me that or whatever. It's not true. Girls should be in charge. Boys are irresponsible. Just Drake and Josh really though. I: So for example Daniel- Do you think he's like these boys? J: He's different. He's always happy, cheerful, wants to sing. He always wants to talk to me. He's happy and he enjoys his lunch. I: You said that Drake and Josh aren't respectful. Is Daniel respectful? J: Yeah. He listens to his teacher. He does everything he's supposed to. Drake isn't respectful because he calls people's names- like Meghan.	I'm not sure this was a good question. I'm trying to link these larger theoretical concepts to things in her real life but I'm worried I'm getting too "teachy" like trying to "prove" some of her assumptions in a way….. I want to think more about this and see if I can leave more silences in future discussions to allow more time for her processing. This reminds me a of the article about "acceptable students" vs. "unteachable students" and constructions of gender.

Appendix C

Narrative Memos

Rae Leeper
Narrative Memoing (#1)
March 10th, 2016

When I'm working with a particularly hard to reach student I try to become as neutral as possible. I look for windows of competency and assume that all of their behavior is intentional communication. Instead of trying to stop something undesired, I want to understand why a student is doing something? What purpose is it filling for them? I spend a significant time observing students and when I think I understand a little about their profile and interests I join them slowly.

With adults I wonder if I often go in with very different expectations. Since it is my job to oversee the classrooms, I want to ensure that each student has the best day that they can. That means that the staff need to be attuned, patient, respectful, and curious. I can be very patient with both adults and students, however, I realize now that I expect growth in adults. If I don't "read" them as evolving I begin to make assumptions.

Catherine is a Teaching Assistant that I do not understand. I can't read her affect and I don't understand her intentions. I find myself become quite frustrated with her and when I'm trying to coach her it's hard to be present and to quiet the voice inside my head that says, "She's just not getting it." As an experiment I wonder how my interactions and interventions with Catherine would shift if I approached her from a more strength based perspective? How would it feel to reframe her behavior in a way that I would for the students?

Deficit Lens:
Catherine did not speak much in the hour that I was there. Most of her interactions with students surrounded food and toileting routines. She paid particular interest to Terry, an 8 year old boy who communicates with gestures and pictures but no words. Catherine seemed interested in getting the child to eat. At times the child seemed interested in this project but at other times it seemed that Catherine was initiating the eating. Why does it matter if Terry eats pretzels? During the 30 minutes with this child, Catherine does not smile. Her affect remains flat. She is calm but it is difficult to know if she is interested in Terry or simply going through the motions. I try my best not to look directly at her as I think I make her nervous. It drives me crazy that she doesn't smile, use any affect, or make the interactions a participatory interactive back and forth. She feels cold towards the children. I'm also not convinced that Terry even wants the food. I think it's a way that he knows how to initiate. Catherine seems to take the student's communication in very literal ways. Terry will point to his lunch box and the next 10 minutes will be Catherine opening the lunchbox and offering food items to Terry. Why won't she help him expand to another interest?!? Several times another student tries to initiate with Catherine. Catherine does not respond until the child goes to the classroom door and points to the bathroom. At this point Catherine takes another child to the restroom. Terry comes over to me and a give his foot a little squeeze. He smiles at me, does a circle around the room and comes over and lifts his foot towards me again to reinitiate the game. Terry has so much potential that I don't think Catherine

sees. I see Catherine as focused on concrete skills that she can help a child accomplish but I don't see her engaging the child during these interactions. I got Terry joyfully engaged in 1 minute. Why can't Catherine?

Strength Based Lens:
Catherine is a quiet Teaching Assistant. She has a calm demeanor and does not overwhelm the students with language. She is particularly drawn to students who communicate in alternative ways that do not involve spoken language. Often this is hard for new staff members to feel connected with harder to engage students so I give Catherine credit for her attempts to connect with these kids. Catherine seems particularly interested in helping students to accomplish their goals in concrete tasks such as toileting and feeding routines. If a child motions to their lunch box, Catherine picks up on the communication easily and will help a child to follow through with their intention. I wonder why this feels important to Catherine? Does she stick with it to help a child to finish what they started? Does she see this as a way to make them feel like their communication is powerful? Feeding is a very powerful caregiver instinct. Perhaps Catherine displays her warmth by cleaning the children, helping them to the bathroom, and feeding them. These are all basic needs that often have a very nurturing role. Maybe this is how Catherine feels helpful? Catherine does not rush Terry to finish his snack. She sits with the snack in her hand and looks to Terry to initiate that he wants more snack. She does not become distracted by the other children in the room, although several of them do tap her or say her name. When a child needs to use the bathroom and initiates by pointing to the door, Catherine puts away Terry's snack and helps the other child to the restroom. Catherine is keenly aware of the students (ADL) needs. I wonder how Catherine feels when she's helping a child to accomplish these tasks? How does Catherine understand her responsibilities and role in the classroom?

This task leaves me with much to consider. Instead of focusing so much on Catherine changing, maybe I need to change so that our relationship can grow?